DISABILITY, IDENTITY AND ASSISTIVE TECHNOLOGIES: A SOCIOLOGICAL STUDY OF 'ORTHOTICS' AND 'PROSTHETICS' FOR THE ORTHOPEDICALLY CHALLENGED

A Thesis Submitted to the University of Hyderabad in Partial Fulfilment of the Requirements for the Award of the Degree of

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IN

SOCIOLOGY

BY

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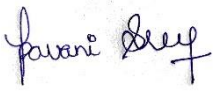

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ABBREVIATIONS

ADL: Activities of Daily Living

ADIP: Assistance to Disabled Persons in purchase of fitting Aids and Appliances

AFO: Ankle Foot Orthosis

ALIMCO: Artificial Limbs Manufacturing Corporation of India

ALMC: Artificial Limb Manufacturing Corporation

ATs: Assistive Technologies

ATDs: Assistive Technology Devices

ATDPA: Assistive Technology Device Predisposition Assessment

ATOMP: Assistive Technology Outcome Measurement Project

CATOR: Consortium for Assistive Technology Outcomes Research

CDC: Centre for Disease Control

CDT: Critical Disability Theory

CPWD: Central Public Works Department

CRPD: Convention on the Rights of Persons with Disabilities

DEPWD: Department of Empowerment of Persons with Disabilities

DRC: District Rehabilitation Centers

EADL: Electronic Aids of Daily Living

EQA: Equality ACT

FIM: Functional Independence Measure

FRDU: Fife Rheumatic Diseases Unit

GDP: Gross Domestic Product

HAAT: Human Activity Assisstive Technology

HKAFO: Hip- Knee-Ankle- Foot Orthosis

ICF: International Classification of functioning, Disability and Health

ICIDH: International Classification of Impairments, Disabilities and Handicaps

ICT: Information and Communication Technologies

IDEA: Individuals with Disabilities Education Act

IMS: Institute of Medical Sciences

IMS-ALMU: Institute of Medical Science – Artificial Limb Manufacturing Unit

IoT: Internet of Things

IQ: Intelligence Quotient

JAWS: Job Access with Speech

KAFO: Knee- Ankle – Foot- Orthosis

MCleg: Microprocessor Controlled C leg

MoSJE: Ministry of Social Justice and Empowerment

MPT: Matching Person and Technology

MRO: Municipal Revenue Officer

NCD: National Council on Disability

NCHS: National Center for Health Statistics (NCHS)

NIDRR: National Institute for Disability and Rehabilitation Research

NSSO: National Sample Survey Organisation

NVDA: Non- Visual Display Access

OBC: Other Backward Caste

PIADS: Psychosocial Impact of Assistive Devices Scale

POP: Plaster of Paris

POC: Point of Care

PTSD: Post- Traumatic Stress Disorder

PWDs: Persons with Disabilities

PWD Act: Persons with Disabilities Act

PWIs: Persons with Impairments

QOL: Quality of Life

QUEST: Quebec User Satisfaction Rating Scale with Assisstive Technology

RCI Act: Rehabilitation Council of India

RO: Registered Organisation

SACH: Solid Ankle, Cushioned Foot

SCI: Spinal Cord Injuries

SER: Socio Economic Rehabilitation

TBI: Traumatic Brain Injury

UDID: Unique Disability ID/ Unique Identification of Disability

UN: United Nations

WAI: Web Accessibility Initiative

WHO: World Health Organisation

CHAPTER 1

Disability in Perspective

Introduction

Disability, thanks to the efforts of the activists and academia, has evolved from an individual centric perception to a social category. Social construction of disability adopted by the academia, activists and policy makers is based on the perception that it is society that perpetuates exclusion and denial of rights to persons with impairments. Disability is treated as a social construct by the rights activists demanding for equal rights and opportunities for persons with disabilities.

Abilities and skills differ from individual to individual and those who make best use of them will survive and sustain. If this was the classical argument as far as PWDs (Persons with Disabilities) is concerned, the social model of disability suggests that abilities and skills are socially conditioned. Irrespective of the inborn abilities or skills if the wider social context does not create conducive conditions for expression and utilization the abilities and skills remain unutilized leading to the suboptimal form of living. The debates on merit, in the context of reservations could be a parallel to the debate on abilities and skills of PWDs.

Disability is identified as a condition which limits an individual in his or her participation in some type of field or action, due to the existence of deficiency. The existence of a lack, therefore, implies a difficulty or obstacle for the individual's participation and performance in the socially constructed roles and responsibilities. Due to disability, PWDs suffer from various difficulties in different aspects of their lives. Unfortunately, the normative discourse considers lack or deficiency in an individual as absent and not as a difference in the spectrum of abilities and skills. Marking the body and construction of an identity based on lack or deficiency is problematic for sociologists who call it stigmatization.

The word disability is not limited to the clinical and health fields, and its implications are more related to society at large: urbanism, architecture, politics, etc. Disability is multitude depending on the physical and mental implications, and the nature of the problems faced by the disabled people. Physical and motor disabilities describe any type of limitation generated by a decrease or elimination of motor or physical abilities, such as the physical loss of a limb or its usual functionality. This type of disability arises in the context of spinal problems, traffic

accidents, and trauma, a medical illness that results in physical limitations, amputations, congenital malformations, or cerebrovascular accidents.

Disability connotes human diversity. Vilification of lack or diversity is pervasive across cultures in the world. Disability can be temporary just as much as it can be permanent. It can represent an injury, a chronic disease, or a birth condition. Disability as a social category does not simply mean handicap or impairment. Limitations that are seen as disabling can include any of a number of heterogeneous groups of conditions. Social disadvantages, physical handicaps, sensory issues, and even learning disorders can all be seen as disability depending on the operational definition. The underlying theme, in all cases, is impairment.

Sensory disability refers to limitations derived from deficiencies in any of the senses that allow people to perceive the environment, whether external or internal. The most common are visual and hearing impairment, though any sensory organs have the potential to be defective or damaged. Intellectual disability is defined as a limitation of mental functioning that hinders social participation or autonomy in areas such as school or work. One common definition of this disability involves having an IQ (Intelligence Quotient) below seventy. These disabilities can influence different cognitive and social abilities, varying widely from person to person. There are different degrees of disability, which have different implications for the individual's independence.

The term disability evolved with the active engagement of activist and advocacy groups in the UN (United Nations) on the issue of marginalization and oppression of PWIs (persons with impairments) by the society. The UN documents 'The World Programme of Global Action on Disability' of 1981 and the 'Standard Rules on the Equalization of Opportunities for Persons with Disabilities' of 1993 set the stage for introducing the term disability founding up on the principles of human rights for persons with disabilities. Proclamation of the Convention on the Rights of Persons with Disabilities in New York on December 13, 2006, as the First Convention hastened the process of bringing legislations in the UN member countries. The United States proclaimed the first Convention of Human Rights of the twenty-first century. PWDs were finally witnessing change, after lengthy struggles and historical exclusions. The proclamation stated that the social disadvantages of persons with disabilities should be diminished and that they should be encouraged to participate in all social spheres, such as the political, social, and cultural (Dussan P, 2010).

The medical model which prevailed till the evolution of social model referred individual impairment and lack as a disease that can be corrected or treated. The aim of the efforts by the medical personnel were to achieve 'normal' functioning. The aim was also to rehabilitate and achieve functionality like 'others', capable of becoming a valuable member of the society. In this model the person with a disability requires clinical care provided in the form of individual treatment, targeted at curing or improving the symptoms of the subject, concentrating on the consequences of the disease (Stainton and Donagh, 2001).

The medical model was enshrined in the ICIDH (International Classification of Impairments, Disabilities and Handicaps); a manual of classification of the consequences of disease, the ICIDH, 1980, of the World Health Organization. This international classification distinguishes between deficiency, disability and handicap (Stainton and Donagh, 2001).

The medical model refers to impairment as a loss of a function, whether it be mental or physical. Deficiencies include disorders in all organs, from the limbs and internal organs of the torso to the brain and nervous system. Examples include blindness, inability to move, and deafness. In the mental realm, deficiencies may include mental retardation and chronic schizophrenia, among others. Disability is thusly defined as a lack of normalcy in a person's abilities, or rather the lack of ability to perform actions otherwise seen as normal. Disabilities are defined as disorders based on how they affect life of a person; some examples of disabilities are difficulties in seeing, hearing, or speaking normally; to move or climb the stairs (Connor and Valle, 2017).

Handicap roughly translates to disadvantage, especially as a consequence of impairment, and is directly linked to a person's limitations. The terms "handicapped" and "disabled," while not synonymous, are often applicable to the same or similar groups in accordance with the medical model. Disability is a description of the social and economic side of a person's situation, while the handicap is the limitation itself (Connor and Valle, 2017). However, these definitions of the ICIDH 1980 were subjected to all-round criticism as they do not adequately treat individual factors and relevant social factors in determining the disability. This led to the emergence of the social model that tries to correct what was missing in the medical model (Ripolles, 2008).

Social model proposes that disability is not a personal attribute but the result of social relations as it places importance on external aspects and the social dimension in both definition and treatment of disability. Social model provided a phenomenal shift in the approach of society

towards PWIs paving way for public policies and legislations aiming at providing equal opportunities for PWDs (Jones and Sloane, 2012).

The ICF (International Classification of Functioning, Disability and Health) in 2001 states, "performance is an umbrella term encompassing all body functions, activities, and participation; similarly, disability is an umbrella term for impairments, activity limitations or participation restrictions" (ICF, 2001, WHO, 2001).

We can therefore see disability as universal, in the sense that every human will be disabled at some point whether due to temporary injury, old age, etc. The ICF recognizes that capacity can change over time and that even the concept of disability itself is subject to evolution over a wide context of reference.

The term "impairment" remains, but new dimensions referred to as "activity limitations" and "participation restrictions" are introduced. Disability is not restricted to being a physical state inflicted upon a person via some sort of accident, but is instead characterized as an experienced limitation. The conceptualization becomes less one-sided as a result.

Assisting with disability means, among other things, providing education, occupational choices, and social rights. These social rights include the right to legally represent oneself, the right to freedom, and recognition of the individual's contributions (Anderson, 2004).

Locomotor Disability

Disability can be physical, sensory, mental, emotional, developmental, etc. Some persons may even experience any combination of inter-connected disabilities, so they can sometimes be difficult to categorize. Each year, thousands of individuals experience any number of the various styles of disability resulting from an accident or from aging or chronic disease. A 2010 estimate showed that over a billion people around the world fall under these forms of disability. Mobility problems, or rather locomotor disability, seemed to be the most prevalent (Sund, Iwarsson, Andersen, & Brandt, 2013).

The demographics of disability within the Indian context is measured through the statistics collected by the National Sample Survey Organizations (NSSO) and the Census of India, which collect data from around the country pertaining to the types of disability experienced by citizens, as well as their magnitudes. According to NSSO (2018), "The survey covered a total of 576,659 people-402,589 in rural areas and 173, 980 in urban areas The report states that the

prevalence of disability in India, or the percentage of persons with disability in its population, was 2.2 percent in 2018- 2.3 per cent in rural areas and 2 percent in urban areas (http://Pib.gov.in)." Whereas in the Indian Census of 2011 it is estimated that 2.7 percent of the population are stricken by some form of disability. The entire number of persons tormented by a motor disability is 54,36,826. Out of these men 33,70,501 and women are 20,66,325 (http://CensusIndia.gov.in).

Census defines locomotors disability as an individual who is either missing one or more limbs or is unable to use their limbs normally without external devices or outside help. This can also include the absence or deformation of critical extremities like digits, or someone who cannot move without the assistance of another person or the assistance of a stick, etc. Being unable to lift or manipulate small objects comfortably is also seen as a sign of disability.

Arthritis and other abnormal movement disorders such as invariable limps are also categorized under movement disabilities. The 2011 Census expanded the ambit further to include a wider variety of conditions, including hunched backs, dwarfism, permanent muscular problems, involuntary movements, balancing issues, permanent loss of sensation, and even fragile bones under the umbrella of movement disorders.

NSSO defines locomotor disability as including persons with missing or unusable limbs or parts of limbs as well as those with physical deformities such as deformed spines, etc. The Rehabilitation Council of India (RCI) Act, 1992, defines locomotor disability as "an individual's inability to execute distinctive activities associated with moving both the self and objects from place to place, and such inability can result from any affliction of bones, joints, muscles, and nerves."

The PWD Act 1995 describes locomotors incapacity as "a disability of bones, joints, or muscles leading to substantial restriction of the movement of the limbs or any type of brain disorder."

Both medical and social definitions of disability treat it as a condition that only exists in relativity to social and/or physical limitations. Unfortunately, these definitions do not account for disabilities that are constructed by society and thusly only disabilities from the context of an insider's point of view (Thomas and Smith, 2008).

The medical model prioritizes the definitions employed by specialists and physicians. The social model gives priority to those with disabilities, allowing for them to converse about their condition, and legal and social needs openly. However, disability has to be considered a

universal issue that concerns all persons. It is not simply a tragic event that happens to someone and is then over. Disability is a real and present human condition that could step into anyone's life at any point in time.

Assistive Technologies

The utilization of new technologies has become widespread across all stages of life, from fertility conception to the last breath. It is widely acknowledged that such excessive and zealous connections between technology, medicine, and human development have sparked heated debates about the ethical implications of such practices. The impact of the latest technological advancements on those living with disabilities is especially multifaceted; on the one hand, it is possible for such technologies to be used to better the physical and social functions of a person living with disabilities, and on the other hand, it is possible for this technological upgrading to alter the way disability is perceived in society.

It is evident that new technologies have had a substantial positive impact on the lives of those with perceptual disabilities. For instance, navigation devices have enabled blind individuals to navigate open and closed spaces with greater autonomy and efficiency than previously possible with white canes or guide dogs. Additionally, vocal synthesis, visual devices and audio prosthesis have opened the door to a variety of cultural and entertainment activities, such as the use of the internet, movies, paintings, architecture and music. This has enabled disabled individuals to partake in activities that may have been previously inaccessible, thus demonstrating the impressive extent to which technological advancements have benefited those with perceptual disabilities (Kushwa, 2017).

It is expected that persons with disabilities will identify their own unique impairments, rather than seeing them as part of their personal and social identity. There is a desire to support the development of such individuals, however, the majority of information sources available to disabled people are organisations that promote new products through their publications or web pages that are easily accessible as the knowledge is limited and only available to those with the financial means to buy the latest technologies and healthcare options. Unfortunately, the cost of these advanced tools and treatments are often extremely high, creating a poverty gap for families with a disabled member (Braithwaite-Mont, 2009).

No matter how specific the medical condition is, new technologies have significant implications in terms of prevention and treatment. In the sphere of medical prevention, there

are modern screening techniques to allow for early diagnosis. Academic research has demonstrated that beginning therapy sooner yields better outcomes. Genetic technologies are increasingly being used as diagnostic tools to explore the correlation between genetic characteristics and the risk of medical conditions. When it comes to supportive and therapeutic technologies, people with motor impairments can rely on prostheses, rehabilitation machines, orthopaedic appliances, and even wheelchairs, brain-computer interfaces, resuscitation methods, drugs and stem cells if needed.

Epigenetic research is exploring the part the environment has in enabling people with disabilities to draw on capabilities from their impairments. The advent of new technologies can offer disabled people opportunities to enhance their abilities, to empower their body or particular organs and functions, and to set new parameters for non-public identity. As technology erases the distinction between illness and good health, it becomes more difficult to distinguish between the normal and abnormal, thus providing a real opportunity to reconsider our approach to disability. Thanks to the emergence of new technologies, people with disabilities can be empowered to access the world unrestricted by disability.

Rather than viewing disability as a negation of identity, it should be seen as an integral, dynamic part of a person's non-public identity, which is subject to change over time and in different contexts. Information and communications technology (ICT) enables quick access to new data, and is beneficial to those with physical impairments as well as those with social, cultural, and political disabilities who are limited by their circumstances.

In addition to aiding disabled individuals, new technologies can alter how disability itself is viewed. For instance, between the 1970s and 1990s, medical scientists started to create tools for the direct study of human brain activity, such as Electroencephalogram (EEG), Positron Emission Tomography (PET), Magnetic Resonance Imaging (MRI) and its Functional variant, Functional Magnetic Resonance Imaging (FMRI), as well as magnetic and electrical stimulation devices like Trans-Cranial Magnetic Stimulation (TMS) and Trans-Cranial Electrical stimulation (TES).

It has been established that those certain areas of the brain, which were once assumed to be solely dedicated to one particular sensory modality, are in fact capable of being activated through multiple perceptions in a variety of situations (Ricciardi et al., 2009; cited in Kushwa, 2017). This example highlights the fact that there is no single, definitive brain model and that

the plasticity of the brain is such that normalcy is not a permanent state, but rather a constantly shifting balance that is continuously affected by our experiences.

Generally, new technologies are attempting to integrate our understanding of the physiological and social elements that affect behavioural advancement with the anatomy of the operational brain. This combined comprehension of the mechanisms involved in emotional and cognitive development could potentially open up fresh possibilities for the evaluation of the human significance of differently-abled individuals as deserving members of humanity. The advancements in technology have enabled us to move beyond the standard dichotomy of medical and social models of disability, thus avoiding the two traditional extremes of wholly attributing disability to social factors and considering disability just through a one-sided medical perspective that views the body as a detached, palpable entity, separate from the self (Hughes and Paterson, 1997).

Exploring the potential of an electric wheelchair to transform a disabled individual's life is certainly a worthwhile endeavour. This device can grant autonomy to a person who otherwise would have to depend on others for mobility, allowing them to reclaim their independence. Furthermore, this newfound independence can result in a better connection to oneself, to others, and to the societal values that are so essential for a sense of belonging.

It is plain to see that technology can be a beneficial aid that improves limited capabilities in human beings. By creating health care devices with advancement in technology, people with special needs can identify the best possible solution to lessen or remove their handicaps, which will ultimately benefit the entire society. The potential difficulties that may emerge between technology and disabilities can be addressed with specific user-friendly practices, thus transforming the relationship between technology and its users from functional to social and effective. Sherry Turtle refers to these technologies as relational artefacts, which "prompt their users to look upon them not as tools, but as companions, as entities in their own right" (2005, cited in Kushwa,2017). In India, the sphere of assistive technology for individuals with locomotor disabilities has largely been an unstructured and unregulated environment.

It can be reasonably assumed that assistive devices and technology are indispensable in the lives of those living with an impairment. Through such aids, these individuals are able to surmount the constraints of daily life, become more involved, and join in with their families and society. Ultimately, these tools and technology lead to increased autonomy and a better quality of life for the disabled.

Following are some detailed examples of aids & assistive devices given below:

Alternative and Augmentative Communication Devices (AAC): Devices such as speech generating devices, voice amplification aids, and communication software are of great assistance to individuals with speech impairments or those who have difficulty projecting their voice. Furthermore, for visually impaired persons, there are magnifiers, Braille or speech output devices, large print screens, and closed-circuit televisions which can be used to enlarge documents.

Daily Living: These self-help aids are designed to assist with activities such as eating, bathing, cooking, dressing, toileting, home maintenance, and more. Examples include specialized eating utensils, adapted books, pencil holders, page turners, dressing aids, and tailored personal hygiene aids.

Digital Aids: This category includes tools such as headsticks, light pointers, modified or alternate keyboards, pressure, sound and voice activated switches, touch screens, specialized software, and voice-to-text software, which allows individuals with disabilities to use computers effectively. Moreover, speech recognition software is also included.

Environmental modifications: Structural modifications that eliminate or diminish impediments, for example, inclines, lifts, adjustments in the restroom to make it open, programmed entryway openers, amplified doorways, and so on can be implemented.

Mobility/Transport: Assistive devices that facilitate locomotion, such as electric or manual wheelchairs, adapted vehicles, scooters, crutches, canes, and walkers, can assist people in moving around their environment.

Prosthetics and Orthotics: The use of artificial limbs, braces, splints, and other orthotic aids for the purpose of replacing or supplementing body parts is known as prosthetics. Such aids can also be used to help those with cognitive impairments or deficiencies, like audio tapes and pagers which serve as reminders.

Recreation: Adaptive technology to facilitate involvement in social and cultural activities, such as audio descriptions for films and modified controls for video games.

Seating: Using adapted seating, cushions, standing tables, positioning belts, braces, and wedges to support posture, along with other devices that provide body assistance, can help individuals accomplish a variety of everyday tasks.

Vehicle Modifications: Adaptive driving aids, hand controls, wheelchairs, and other lifts can be used to modify vans or other motor vehicles for personal transportation.

Special Controllers: Electronic systems can be used to facilitate the manipulation of different gadgets, including phones, TVs, or other equipment which can be activated through pressure, eyebrow motion, or respiration.

The LOMAK (Light Operated Mouse and Keyboard) was specifically designed to support people with disabilities in New Zealand. This keyboard features a hand or head pointer that controls a beam of light that highlights and then confirms the desired key or mouse functions. The input accuracy is increased and the possibility of errors is reduced as the system only confirms the selection after the key is highlighted. As it is easy to install, use, and manage, it is an ideal addition to any work environment. Furthermore, it requires minimal technical support from a systems perspective (Sobh, 2007). In order to further improve the accessibility of the World Wide Web, the Web Accessibility Initiative (WAI) was established by the World Wide Web Consortium (WWW). This organization is dedicated to the concept of "inclusive design," which is meant to ensure that people with disabilities have access to the following (https:// W3.Org/WAI)

This includes features such as:

- Presents the same content in different ways.
- Ensures content is easy to see and hear.
- Designs pages so that content appears and operates in predictable ways (WAI, https://W3.Org/ WAI).

Transfer Devices

Caregivers often utilize a variety of tools to move patients with impaired mobility between beds, to and from wheelchairs or chairs, to and from commodes, toilets, shower benches, stretchers, and automobiles. These tools include transfer belts, transfer boards, pivot discs, vehicle grab handles, bed slings, sliding pads, ceiling-to-floor grab bars, small assist rails and trapeze stands. The pivot discs help the patient to transition between directions without slipping on the floor, the bed slings aid in positioning the patient, the sliding pads make turning over in bed easier, and the grab bars are beneficial when getting up or sitting down.

Walkers

A walking frame or rollator offers additional support to users for stability when standing or walking. The frame is waist-high and roughly 12 inches deep, and needs to be slightly wider than the person using it. Additionally, walkers can be adjusted to different heights and have different sizes to accommodate different people, such as children or heavier individuals.

Wheelchairs

Wheelchairs and/or walkers are mobility aids which provide an electrically or manually propelled means of transportation, as well as a seating system, for those with impaired mobility. These devices are intended to give individuals with reduced mobility the ability to perform essential daily activities such as eating, toileting, clothing selection, hygiene, and bathing. They provide an alternate method of movement for those with both sitting and walking disabilities.

Robotic wheelchairs are a unique subcategory of wheelchair. Semi-autonomous mobile robots have, historically, been geared towards implementing surveillance, delivery, and other related duties. However, they can also be employed as an assistive technology, performing an entirely different role. For instance, power wheelchairs provide support to people with reduced upper body strength, and who are unable to operate a manual wheelchair.

Prosthesis

An artificial device created by humans to mimic a lost body part is known as a prosthesis. This device strives to restore the appearance and functioning of a missing limb, such as a hand, arm, leg, or foot, resulting from a congenital defect or trauma. The range of prostheses includes dentures, wigs, and plastic heart valves, with the main focus being on limb prostheses. The type of artificial limb to be used is largely determined by the scope of amputation or loss of the limb in India (Maiya et al, 2019).

Social Relevance of Assistive Technology

Assistive Technology (AT) is an essential element in an individual's life, providing a range of benefits to those with disabilities, as well as those without. Technologies such as software tools, artificial limbs, and wheel chairs, can significantly improve the functioning of individuals with impairments and activity restrictions (Reddy, 2012). It is a popular misconception that ATs are only used by persons with disabilities, yet an increasing number of ATDs are becoming available to suit the needs of those without disabilities too. Everyday items such as calculators,

pointers, highlighters, keyboards, and electronic reminders are all examples of ATs being used by all. As the Internet of Things (IOT) continues to develop, the scope of ATDs is set to expand, being accessible to both Persons with Disabilities (PWDs) and Non-PWDs.

Prior to the development of stairs, escalators, and analogous technology, society had to find alternative methods for navigating between different levels of a building. Frequently, people may not realize how much they depend on stairs for their daily activities, yet for some, using stairs is not possible. Businesses are rarely held liable for not providing an accessible means of travel for those with disabilities, even though the use of elevators and ramps could make it possible for them to move around freely. The incorporation of elevators and ramps in buildings raises the number of individuals who can live their lives with less difficulty due to disability, and in fact, elevators can be seen as an Adaptive Technology that can be utilized by anyone. A relatively novel concept is to examine how to make society more inclusive, instead of solely focusing on identifying what is wrong with the body as many medical models do. The utilization of other assistive technologies, such as eyeglasses, has become widely accepted. In the past, a person with poor vision would have been significantly disadvantaged, however, with the advent of corrective surgery, glasses, and contact lenses, vision-based disabilities are now generally perceived as 'normal' in everyday life (Lammichane, 2015).

Advances in Information and Communication Technologies (ICT) have created numerous devices that offer people with disabilities the potential to increase their social, cultural, political, and economic integration in their local communities by expanding the number of activities they can participate in. As technology continues to develop, Information and Communication Technologies (ICTs) provide novel opportunities to fulfill our obligation to those living with disabilities. The emergence of specialized assistive technologies, like microprocessor-controlled prosthetics or digital hearing aids, has been a major breakthrough in the field. The use of more prevalent technologies, like computers, tablets, and smartphones, can make social and economic inclusion of persons with disabilities. In today's post-modern, tech-driven culture, the widespread adoption of Bluetooth technology among the vast majority of people has presented a bright outlook for those who are hearing-impaired. Likewise, progress in medical technology with respect to the design of hearing aids has rendered the disability less visible and less socially isolating. It can often be challenging to identify whether the individual passing by has a hearing aid or a Bluetooth device on. The medical model seeks to alter the condition of the individual in order to assist them in managing their functional

problems, thereby allowing them to better adjust to their roles in society which remains the unchanged aspect of this approach.

Access to Assistive Technology in India

Assistive technology encompasses products and associated services that facilitate the functions of those with disabilities. It can be instrumental for the development and health of disabled people in the involvement in different aspects of life. These include mobility, communication, homework, self-care, family relationships, education, and involvement in play and recreation. Assistive technology can boost the lives of both persons with disabilities and their families (Nicolson et al, 2012) and implies the difference between inclusion and exclusion, between appreciation of rights and deprivation of freedoms (Borg, 2013).

Each sort of assistive technology needs its methods of assessment in how the item is adapted, modified or fitted. It is essential that the people engaged in service delivery have the understanding needed to avoid potential damage correlated with inaccurate valuation and fitting. Hence, appropriate services can have a substantial impact on the result of using assistive technology (Scherer et al, 2007).

Assistive technology is a strong tool for increasing independence and expanding participation. It enables individuals with disabilities to get mobile, interact more efficiently, see and hear better, and actively engage in learning operations. It also promotes people accessing and enjoying their freedoms, doing things that they value, and bridging disparities between persons with and without disabilities. It establishes the means of accessing and participating in instructional, social and recreational possibilities; empowers higher physical and mental function and improves self-esteem; and decreases expenses for academic facilities and individual supporters (WHO, 2011; Ground et al, 2010). Assistive technology can "decrease any need for official support services, decrease caregivers' time and physical strain, and discourage falling, injury, further impairment, and premature death" (WHO, 2011).

Making ATs that are available, accessible, affordable, adaptable, acceptable and of adequate quality involves the effective use of often restricted resources. The resources are interrelated, including people, equipment, techniques of manufacturing, and systems of service delivery. Materials and human resources that are available often determine feasible techniques of production while service delivery systems determine which materials and manufacturing

techniques can be used, especially for repair and maintenance. The size of the market defines whether economies of scale can be exploited.

Too often, assistive technology has been a missing link in the chain of preconditions that allow disabled persons to lead a life in which they appreciate and practice their freedoms rather than being deprived of them. While governments have the main responsibility for ensuring access to assistive products for people with disabilities, global collaboration in the field of assistive technology can also be a critical catalyst (https://www.unicef.org/disabilities/files/Assistive-Tech-Web.pdf).

Nationwide campaigns and policies have been assessing the actual number of disabled persons and the types of disabilities to provide them equal opportunity and independent lives with dignity in all aspects of life. The Department of Empowerment of Persons with Disabilities (DEPwD), Ministry of Social Justice & Empowerment has conceptualized the "Accessible India Campaign" (Sugamya Bharat Abhiyan) one of the campaigns that seeks to enhance the awareness of disability issues, as well as advocating for acts and legislations promoting and strengthening the wellbeing of persons with disabilities.

The development of various systems and devices, such as LOMAK, WAI and Information and Communication Technologies (ICT), have the capability of augmenting the participation of individuals with disabilities in the social, cultural, political and economic aspects of their communities by expanding the range of activities they can engage in. As the world continues to become more digitally oriented, Information and Communication Technologies (ICTs) provide novel means of fulfilling the obligation to individuals with disabilities.

There has been a remarkable progress in the construction of specialized assistive technologies, including microprocessor-controlled prosthetics and digital hearing aids, yet general-purpose technologies, including regular computers, tablets and smartphones, present substantial possibilities for larger-scale social and economic integration of individuals with disabilities.

Information and Communication Technologies (ICTs) in general use can have a remarkable impact on the lives of those with disabilities. The Indian government has been providing support to disabled people in purchasing durable, technologically advanced aids and appliances that are up to ISI standard, to help them become more physically, socially, and emotionally independent by reducing the adverse effects of disability. Banks owned by the public sector

are set to provide financial aid to private, public, and joint sector companies that manufacture high-tech assistive devices for the disabled.

Under the 'Make in India' program, the Artificial Limbs Manufacturing Corporation of India (ALIMCO) - operating as part of the Department of Empowerment of Persons with Disabilities (DEPWD) and Ministry of Social Justice and Empowerment (MoSJE) - is engaged in the manufacture of a variety of new generation lower limb prosthetic systems on a large scale. ALIMCO aims to generate technologically sophisticated prosthetic systems that enhances the autonomy and mobility of leg amputees from all walks of life in India. ALIMCO has been supplying assistive devices to empower and restore the dignity of the disabled, catering to orthopedic impairment, hearing impairment, visual impairment, and delayed intellectual growth throughout the country.

According to ALIMCO Report (2021-2022), the corporation distributed 4,47,843 appliances to 2,54,964 beneficiaries through 773 camps during 2021-22 under ADIP (Assistance to Disabled for purchasing/fitting of Aids/appliances), ADIP-SSA (ADIP- Sarva Siksha Abhiyan), RVY (Rashtriya Vayoshi Yojana) and CSR (Corporate Social Responsibility) Schemes.

Table 1.1: Distribution of Aids and Appliances by ALIMCO

Schemes	No. of Camps	No. of Beneficiaries	No. of Appliances
ADIP	187	93315	132899
ADIP-SSA	429	97742	124217
RVY	83	45336	151209
CSR	74	18571	39518
Total	773	254964	447843

Source: 49th Annual Report 2021-2022

Under ADIP Scheme, the Corporation has distributed 1,32,899 appliances to 93,315 beneficiaries in 187 districts of 27 states during 2021-2022 by following Standard Operating Procedures (SOP) for conducting camps as approved by the Ministry in wake of Covid-19 pandemic threat. The corporation has further distributed 1,24,217 appliances to 97,742 beneficiaries in 429 districts of 18 states under ADIP-SSA Scheme. The Corporation has distributed 1,51,209 old age appliances to 45,336 beneficiaries covering 83 districts of 24 states under RVY scheme, the scheme which is meant to distribute aids and appliances to senior citizens. ALIMCO is also working as CSR Implementation partner for many companies in

empowering the Divyangjan as part of their CSR projects. The corporation has distributed 39,518 appliances to 18,571 beneficiaries under CSR.

Research Problem and Objectives

Medical technology in the case of disability plays a pivotal role in improving the living standards with the aid of assistive technologies such as prosthetics or orthotics. There have been several studies on the use of assistive technologies in promoting activity participation and raise functionality levels among persons with impairments in the western context. However, in India, the sociological literature on the adaptation of assistive technology devices for the locomotor disabled persons is negligible. This study attempts to provide sociological insights into construction of locomotor disability by self, family and medical professionals and in accessing assistive technology.

Objectives of the study are to examine;

- Social construction of identity of persons with locomotors disabilities by the self and family members,
- The assumptions of the medical professionals on bodily impairments of persons with locomotor disabilities and on assistive technologies, and
- The nature of assistive technologies with specific focus on socio-cultural and economic factors influencing access and adaptation among persons with locomotors disabilities.

Research Methodology

Research design is a blueprint, an outline, and a systematic plan prepared for directing a research study. The present study employs both qualitative and quantitative methods.

Sample Selection

All persons with disabilities living in the geographical area of Telangana and Andhra Pradesh constitute the Universe of the study. All persons with locomotors disabilities who approached the Artificial Limb Manufacturing Unit in the Institute of Medical Sciences (IMS) in the year 2015-2016 will constitute the population of the research. In the case of Assistive Technology users (AT's), people who are using ATs for the last one and a half years are taken into consideration.

Research Setting

The Artificial Limb Manufacturing Unit at the Institute of Medical Sciences and Orthofit were chosen for the study. Both these organizations provide assistive devices for the needed. One is a state-run organization and the other one is a private organization.

Sources of Data Collection

This study is based on both primary and secondary data. Primary data was collected from respondents who have locomotor disabilities. These respondents include assistive technology users, who use orthotics like wheel chairs, tricycles, crutches, stick, callipers, Ankle-foot-orthotics, Knee-ankle-foot-orthotics; with mild to moderate deformed limbs; and respondents using artificial legs (amputees). Respondents include children and adults with locomotor disabilities. Respondents of the study also include family members; parents of child respondents and spouses of adult respondents. Respondents also include medical professionals; doctors, physiotherapists, orthotists, and prosthetists.

A semi-structured questionnaire was used to obtain data from the field. The questions were formulated in such a way that participants were given the chance to provide detail responses. In-depth interviews were conducted with respondents with locomotor disabilities in order to gather data on perception of self, perception of others, particularly family members, on them, as a member of the family, their roles and expectations from the family members. In-depth interviews, along with informal conversations, were used to collect data from parents and spouses, of respondents with locomotor disabilities, on their perceptions on a family member who is a locomotor disabled person, social and cultural connotations of disability and as a disabled family member as perceived by kin group, and assistive technologies. Data were also collected on the wider social context which influences their identity and participation.

An overview of the socio-economic backgrounds of persons with locomotor disabilities was obtained by employing the interview method. Interviews were conducted with medical professionals from both organizations. Analysis of case studies and first-hand accounts proved to be beneficial in comprehending the geographical, social, cultural, economic, and political issues, as well as the issues pertaining to identification and involvement of individuals with locomotor disabilities who are using assistive technologies. Interviews were conducted in the native languages of Telugu. The information provided by the respondents was recorded using a voice recorder after taking their consent. The duration of the tape-recorded interviews was

30-45 minutes and took place in a closed setting suggested by the respondent. The voice recordings were transcribed and analysed.

Data from medical professionals were collected during their free time. For medical professionals, the researcher used snowball sampling. The core area explored from the interviews of medical professionals is understanding the meaning of disability from their perspective. The secondary sources of data are reports, books, and other relevant sources like the internet. For this study, data were collected using both qualitative and quantitative techniques. The researcher approached persons with locomotors disabilities who are using ATs in both IMS-ALMU and Orthofit. The criterion for selecting the respondents was that, those persons with locomotors disabilities who have been using ATs for the last one year.

Ethical Considerations

They are as follows:

Non-Harmful Procedures

Data were collected through a semi-structured questionnaire, in-depth interviews, case studies, narratives and observation methods. Measures were taken to ensure the process was as comfortable as possible for the respondents of the study.

Informed Consent

The persons with disabilities and the medical professionals were apprised of the aims, techniques, and rationale of the study which might influence their decision to take part or not. They were given full autonomy to opt for participation or not, including the choice to withdraw from the research at any point.

Confidentiality

The identity of the participants remains anonymous in the thesis and the information collected is not utilized for any other purpose than what is needed for the investigation.

Data Analysis

For this study, simple quantitative analysis was used to present brief profile of the respondents. The analysis largely used qualitative methods, including narratives and case studies, describing

lived experiences of respondents and their family members on the social construction of disability and assistive technologies.

CHAPTER 2

Historical and Social Contexts of Disability

This chapter attempts examining disability through a historical and political lens. The concept of disability is not an uncontested universally agreed term but has instead been debated on and improved over the course of human history. The general understanding of disability has evolved through history and is only recently becoming more holistic and inclusive.

Complications in the Discourse

As with any other field of study, disability has been a complex discourse with many nuanced positions and subdivisions. It can be divided into a far greater number of categories than was ever possible in the past due to the gradual expansion of awareness of branching issues and differences within persons with disabilities. In general, disability has been seen as a deviance from the norm rather than as an alternative to the norm, and has as such been utilized in an unflattering light across much of literary history, in particular, where it is often explicitly used unapologetically to act as a character flaw (Snyder and Mitchell, 2001).

Across the world, persons with disabilities face worse living conditions, poor academic participation and high poverty. This is partly attributed to the obstacles that hinder the disabled individual's access to services, specifically health, education, employment, transportation, or information. These difficulties are exacerbated in less favored communities. The problems that disabled persons face in many ways parallel the discrimination that a person might face due to gender or sexuality. Ableism stands in the same mind space as patriarchy and heteronormative views, often defining disability as a 'wrong' trait that needs to be fixed or prevented by any means necessary. It should be noted, though, that some disabilities have started to become their own categories. Deafness, for example, is becoming a recognized issue of language barrier (using sign language as the basis) with less stigma than many disabilities as a result of this trend (Addlakha, 2018 in Srivastava, Asif and Abraham, 2018 ed.).

Persons with disabilities lack equal access to health care, education and job opportunities. Since the introduction of the Convention on the Rights of Persons with Disabilities (CRPD), disability is increasingly seen as a serious issue. It also constitutes a developmentally important issue: there is a growing set of evidence showing that individuals with disabilities are worse off socioeconomically and suffer more poverty than persons without disabilities. Despite the magnitude of the matter, there's insufficient awareness or scientific information about

disability. No universal agreement on definitions has been reached and little internationally comparable information is accessible on the prevalence and patterns of disability. Faced with the lack of data, the World Health Organization (Resolution 58.23, Disability, including prevention, treatment and rehabilitation) requested the Director-General of WHO to arrange a worldwide report on disability supported by the scientific evidence available. The result was the "World Report on Disability", produced in conjunction with the World Bank (WHO, 2011).

According to the Census of India carried out in 2011, there are 2,68,14,994 people who suffer from some type of disability, which represents 2.14% of the total population. In 2016, the Indian Parliament expanded the number of disabilities covered by law from 7 to 21. Through this legislative Act, called the "Law on the Rights of Persons with Disabilities," autism and types of muscular dystrophy were included within the definition of disability, which allowed better treatment of those affected in hospitals located in major cities. Approximately 80 lakh disabled people live in urban centres while 1.80 crore live in rural areas. Of the nearly 2.6 crore people with disabilities in India, less than 1 crore have jobs, while the remaining 1.6 crore remain unemployed. In the light of the fact that the persons with disabilities lack access to education the "Law on the Rights of Persons with Disabilities" makes provisions on positive discrimination such as the reservation of quotas at the highest educational levels and in public employment.

Disability in History

Throughout history Greek architecture has exercised a remarkable influence on building design in the western world, but it was not designed with disability in mind. Consequently, many public constructions still present important deficiencies around accessibility. The conquest of Greece by the Roman Republic meant the assimilation of its cultural legacy and its militaristic, material and hedonistic values. Roman society was based more than the Greek on the exploitation of slave labor in large rural areas and in imperial expansion to obtain prisoners and new farmland. For this reason, they were just as enthusiastic about infanticide. Protected by the Law of Twelve Tables (540 BC) which granted the *pater familias* the right to the life of his sons and daughters, children considered "weak" or "sick" were thrown into the river Tiber or thrown into the cliff of the Trapezia rock, together with the elderly and adults with acquired disabilities. In the Roman Empire, the death of minors with disabilities was no longer common, rather, they were left in the street or in a basket on the Tiber to pass onto whosoever would like to use them as a slave or professional beggar. Children with disabilities received greater alms,

which led to a trade in mutilated children - some of them through brutal surgeries - among adults who exploited them for their own benefit (Salomon, and Murray, 2002).

In Rome, a system of retribution for people with disabilities began to be applied for the first time. Disability due to war was compensated through land for cultivation. They also developed hydrotherapy and physical maintenance techniques for cases of acquired disability, but access to which was limited to the higher classes due to the high cost. During the reign of Constantine (272- 337) institutions were intended to provide accommodation, maintenance and spiritual help to persons with disabilities who had no means of subsistence. The assets of a Roman disabled person could be described as *sui iurispúber* or incapable due to lack of capacity to exercise the rights alone. During that time, people with mental disabilities (that is, those deprived of reason) were called "furious", and those with limitations or poor development of their intellectual faculties were called "mind captus" (Warden, 2019).

Disability has been viewed in various ways throughout the history, depending often on the attitude of society and the position of persons with disabilities in the social context. The most appropriate criterion for differentiating them has commonly depended on status. However recent history has revolved around the dialogues between the medical and social model, considered as the main conceptual references to be used for disability (Stainton T., and Mc Donagh, 2001).

Perspectives on Disability

The medical model focuses on the body of the impaired, and thus on the individual, while making no attempts to implicate the ‘social’. The social model, implicates society for the issues faced by persons with disabilities shifting attention from body to the social. The medical model and the social model should ideally be seen as two sides of the larger issue, i.e., marginalization of PWDs. At the same time, neither is able to comprehend disability fully, and thus they have been criticized for their limitations for the scholars who to subscribe critical disability perspective. The more advanced interpretation of disability was put forth, named as the International Classification of Functioning, Disability and Health (the ICF model). The ICF model understands disability as a combination of both medical and social factors. The idea is to provide a more coherent and cohesive understanding of disability that looks at it as a combination of the physical limitations of the individual and the ways in which those limitations interact with their environment in a socio-political context. In this definition, ‘impairments’ can be problems in body function or social structures or a combination of the

two, with the key that significant deviation from the expected norm or loss of ability is the end result (Reddy, 2011).

The Convention on the Rights of Persons with Disabilities (CRPD) views disability as an interaction between the disabled person and their environment's socioeconomic barriers, which emerges organically from the moments in which an individual's limitations and the society's accommodations appear to be incompatible (Murray and Lopez, 1996).

Policies and systems for the provision of services, including the rules governing the provision of services, can also be obstacles. For example, Salomon and Murray (2002) report that the public health services in Australia do not consider the additional time that was often required to provide services for persons with disabilities; consequently, the hospitals that treated disabled patients were at a disadvantage, as the financing system reimbursed them a fixed amount per patient, ignoring the need for reimbursing for the additional time (Salomon and Murray, 2002).

Disability leads to exclusion from society, not just because of physical factors but also because of social barriers. Disabled persons are less likely to leave their homes on any given day, in part due to the negative attitudes of their loved ones who feel they are 'unfit' to navigate social environments unless it is 'needed.' A disabled person's access to society is determined largely by the decisions and perceptions of their family. This ultimately presents a very real obstacle that limits a disabled person's access to social and political involvement (Chand and Reddy, 2012).

The Medical Model of Disability

The Medical model of disability is an outcome of the Enlightenment period in the late 1700s (Godley, 2011). During the Enlightenment, the focus on scientific and logical progress led to disability being conceptualized in physical terms, resulting in a major departure from the religious perspective. At the end of the 18^{th} century and the start of the 19^{th} century, the invention of technologies like the radio, the telephone, and the television provided people with disabilities, who had limited or no other options, with a more convenient way of life.

Innovations were made in the disciplines of science and medicine as well. This led to a culture which was becoming more cognizant of disability and sickness from a medical angle, with a greater number of choices for remedies and intercessions. The Medical Model provides a scientific and ontological account of disability. This study delves into the physiological aspects

of disability, revealing the physical distinctions between those with and without impairments. The model endeavours to identify a physical impairment within the individual (Karna, 2001; Ghai, 2003). Nagi and other health care agencies, including the World Health Organisation (WHO) and the Centre for Disease Control (CDC), were responsible for formulating the medical model.

In 1976, a major milestone occurred within the medical model. The World Health Organization assembled a commission, overseen by Philip Wood (Barnes, 2009), and developed the International Classification of Impairment, Disability, and Handicap (Oliver, 1990; Ghai, 2015), which has been widely accepted on both the international and national levels. This classification serves as the basis for definitions of impairment, disability, and handicap, among other factors, that are used to determine disability status in the laws of each state.

This classification identifies two primary features of handicap: impairment and disability. Impairment is defined as any kind of loss or abnormality of physiological, psychological, or anatomical structure; functional limitation of the body of individuals (Ghai, 2015). Disability, on the other hand, is the inability of individuals to perform activities that are considered normal for other people. As a result, handicap is understood to place these individuals in an inequitable position in comparison to their peers in society.

The World Health Organization has depicted those with disabilities as being atypical individuals in the general context of human beings. However, Oliver (1990) and Ghai (2015) have expressed their disagreement with this physiological characterization of disability, asserting that it is an individualistic and medically oriented perspective which disregards the social aspect of it. Oliver (1990) has referred to this model as the Individual Model of Disability.

The Medical Model, also referred to as the Charity Model of Disability (Ghai, 2003), is based on a philanthropic outlook and relies on the formation of charity networks by institutions. This perception holds that individuals with impairments are less fortunate and need assistance with everyday activities. Jennifer Keelan has pointed out, in keeping with the Americans with Disabilities Act, that this view generates a dependence on others among people with disabilities. Moreover, it legitimizes the religious view of disability as a mark of God's displeasure and prompts governments to offer institutional care, such as special schools and training centres, in an effort to cater to the demands of a modern industrial society (Ghai, 2003).

It was further understood that individuals with impairment(s) are ontologically and physically restricted. They are endowed at birth with a disability manifesting itself as an abnormal limb, impaired body, or other physical anomalies. Following this, the personal tragedy of disability is seen to be the defining feature of this model (Oliver, 1990; Swain and French, 2000).

In light of the criticisms raised by Mike Oliver, Finkelstein and other proponents of the social model, Thomas (2004) asserted that if one acknowledges the existence of a biologically-generated, pre-discursive force, then it is possible to dispute postmodern social reductionism, biological reductionism and the one-sided social determinism. He emphasizes that scholars such as Oliver, Finkelstein, Mercer, and others have rejected the concept of a distinct entity existing autonomously. Oliver challenged the former way of distinguishing between people with and without disabilities by assigning a body type to individuals instead of focusing on the negative effects of society on them and their inherent humanity (Oliver, 1996).

Other sociologists, such as Colin Barnes and Vick Finkelstein, have offered their own definitions of disability (Oliver, 1990). The third proposition of this clinical model is that disability is a personal affliction and there is no connection with society (Oliver, 1990). It defines them as people with impairment by arguing that impairment is an inherent feature of the body that can be repaired and normalized through medical intervention. The medical field considers disability to be caused by a range of health-related conditions that can be identified, addressed, rectified, and/or eliminated through medical care.

It has been medically determined that disability is a result of both individual impairments and biological illnesses. The medical model concentrates on the impediments of individuals and considers medical treatments or adaptive technologies to permit them to accommodate to society once again. In the medical realm, therapies are typically accepted with openness. Medical treatment that was provided by professionals in institutional settings disregarded the psychological needs of persons with impairments, in addition to their other requirements. The requirements for disability were precise, with attention directed to those with disabilities while the environment remained unaffected. Individuals with disabilities had limited autonomy and were not fully engaged in making decisions concerning their treatment and its course.

This model regards an individual's impairments as an issue, attempting to discover a cure, primarily concentrating on what is wrong with the handicapped individual, without taking responsibility for society to conform to the requirements of those with disabilities. The second interpretation of this model was that those with physical impairments are fundamentally and

physically disadvantaged. They are born with a disability that is manifested in their impaired limb, malformed body, or other physical variations. Following this, the personal tragedy model of disability is used to define this model (Oliver, 1990; Swain and French, 2000).

In response to the critiques voiced by Mike Oliver, Finkelstein, and their colleagues who follow the social model, Thomas (2004) posited that, if one acknowledges the presence of an independently real biological body, which can be seen as the source of a pre-discursive causative force, then one can refute postmodernist social reductionism, biological reductionism, and the single-sided social determinism. He argues that sociologists such as Oliver, Finkelstein, Mercer, and others refute the notion of the existence of an independent entity. Michael Oliver (1996) questioned the traditional outlook of characterizing a personal tragedy based on the distinction between abled and disabled bodies, instead of emphasizing the social disability and humanity of the individuals (Oliver, 1996). Colin Barnes and Vick Finkelstein are two other sociologists who have put forth definitions of the concept of disability (Oliver, 1990).

The Social Model of Disability

The Social Model of Disability is viewed as a major narrative on disability, providing a substitute point of view to comprehend disability. It stipulates the sources of disability located in social and political realms, which was initially proposed by the Union of Physically Impaired against Segregation (UPIAS) in 1976 (Oliver, 1990, Mike Oliver, 1998, Barnes and Mercer, 2004, Shakespeare and Watson, 1997). The emergence of the Social Model has been acknowledged as the decisive counterpoint to the medical model (Barnes, 2009).

The social model of disability declared that medicalization of the body was not acceptable on multiple grounds and proposed a new perspective of disability. For example, according to Oliver (1990), disability should not be viewed as a personal issue and Swain and French (2000) argued that it should not be deemed as a personal calamity. Moreover, Barnes (2009) demonstrated that the term "persons with impairment" was replaced by the phrase "disabled people" to refer to disabled people globally.

Jolly (2012) has argued that the Social Model has led to the implementation of policies which are linked to accessible housing, roads and other state-led amenities for people with disabilities. Barnes and Mercer (2004) have shown that this model is responsible for the state taking positive steps in creating structures and facilities which are accessible for disabled persons.

Furthermore, the conceptual distinction between Impairment and Disability which is attributed to the Social Model is said to have its roots in the women's movement (Shakespeare, 2004; Barnes, 2009; Oliver, 2013).

In the United Kingdom, the Social Model has had a significant impact on the government's policy agenda, as demonstrated by the Disabled Person Services Consultation and Representation Act of 1986, the Disability Discrimination Act (DDA) 1995, Disability Rights Commission Act of 1999, and Equality Act (EQA) 2010. This phenomenon is not exclusive to the UK, as India's Persons with Disabilities (Equal Opportunities, Protection of Rights and Full Participation) Act, 1995 serves as a testament to the Social Model's power to persuade countries to take a proactive approach to bridging the divide between disabled and non-disabled people, and fostering an environment where all individuals can enjoy equal rights. Crow (1992) is known for elucidating a division between impairment and disability which is conceptualized by Ghai (2015) as a dichotomy within the social model of disability's progressive framework.

Oliver (1996) emphasizes the distinction between impairment and disability; the disability of an individual with such impairment suggests that they are missing a limb or have impaired limbs, as well as an absence of organs or an inability to utilize the conventional functions of the body.

Shakespeare (2002) claimed that the incapacity of people with disabilities may be a result of social and external limitations beyond their actual impairment. This model of thought has been a great contribution to the disability movement. It enabled the British public to comprehend the oppression of disabled people by the wider society. This recognition of the issue led to the disabled community being identified as a group that was oppressed in British society (Shakespeare, 2002). Additionally, Shakespeare suggested that impairment alone is not the sole cause of disability (Swain and French, 2000).

Michael Oliver (1998) proposed that impairment is not related to the physical body, but rather an external notion of it, which lead to the formation of the British Social Model of Disability. This idea was furthered by Finkelstein in 1987, who declared that disabled individuals cannot make an impact without representation (Barnes and Mercer, 2004). This line of thinking was also echoed by non-disabled authors, who suggested that those without impairments are unable to grasp the sentiment of those with disabilities due to their lack of direct experience.

In conclusion, Oliver (1990) delved into the lives of the disabled through the lens of disability studies, while Tom Shakespeare (1997) noted the reluctance of non-disabled academics in the field of disability research to take into account the social aspects of impairment, opting instead to focus on the individual and personal tragedy of impairments. He further pointed out that the works of disabled authors, such as Barnes, Finkelstein, and Michael Oliver, were overlooked in favour of this approach (Barnes and Mercer, 2004).

In the 1980s and 1990s, the Social Model was inspired by the Black Rights movements and argued that there should be representation at all levels of society from the disabled community and that they should be treated as the sole representatives of their group. This assertive approach delegitimized the non-disabled as a representative of the disabled people and led to the emergence of the Emancipatory Social Model, which recognizes disabled people as the true representatives of their community (Shakespeare,2004).

The recognition of disability as something more than a medical impairment has been largely informed by the acknowledgement that society can be structured in ways that create unequal opportunities, and that can result in discrimination and stigma. This is a significant development that has transformed how disability is understood, providing a more comprehensive and sympathetic outlook. Despite the benefits of the social approach, it does rely on external recognition of the disabling condition.

The social model is frequently seen as an advanced step in the development of the medical model, with the potential to provide additional legal protections, differentiated rights, ethical committees, and other positive policies that could reduce or remove a number of the everyday limitations imposed on people with disabilities (Smith, 2009).

The ICF Model of Disability

The medical model put an emphasis on rectifying the impairment to allow the impaired individual to fulfil the expected functional roles in society and their family. The social model was one of the strongest forces driving disability activism and civil rights in various countries, particularly in the West, by showcasing the social impediments experienced by the impaired and providing a distinct plan for social transformation. However, it de-prioritized physical impairment and pain, thus overlooking the need for treatment to reduce anguish. Taking into account the restrictions of both the medical and social models, the World Health Organization

created the International Classification of Impairments, Disabilities, and Handicaps (ICIDH) during the 1980s.

The ICIDH separates disabling conditions into three distinct components: impairment (any loss or abnormality in a physical or psychological function), disability (any limitation or lack of ability to execute an activity within the scope normally expected from someone of a certain demographic group), and handicap (a disadvantage for an individual caused by an impairment or disability that prevents them from performing a task which is considered normal for them).

The ICIDH model has been strongly criticized for its suggestion that disabled people are inherently carriers of a deficit, and its reliance on bio-physiological definitions of normality. This classification fails to take into account the social, economic, political, and cultural barriers that exist within the environment that limit the ability of disabled people to perform activities in a normative manner. Moreover, the ICIDH posits a cause-and-effect relationship between types of injury and the functional or organic impairments they cause, as well as the disability that results from diminished functional performance in individual behaviour.

The ICIDH has been met with criticism for its assumption that impairment is the basis of both disability and handicaps, as well as its favouring of medical and rehabilitative interventions. Barnes and Mercer (2004) have argued that this clinical emphasis results in strategies that are focused on adjusting and managing the individual's limitations, rather than acknowledging their social exclusion. In response to these criticisms, the ICIDH was revised and renamed the International Classification of Functioning, Disability, and Health (ICF). The ICF model is designed to be a comprehensive system that incorporates both the medical and social models of disability, offering a holistic view of disability from biological, personal, and societal perspectives (WHO 2001).

Critical Disability Studies

In recent decades the study of disabilities has seen critical shifts, resulting in the emergence of the phrase Critical Disability Studies (CDS) to describe the modern understanding of disability. This term, much like the IDF model, signifies a cultural shift away from polarized models of disability and toward a more comprehensive and analytical understanding. CDS theorists ultimately aim to move away from simple labels and toward a comprehensive and interdisciplinary review of what we know and what needs to be done moving forward. Whether this is a divergence from traditional models or a natural evolution of disability studies as a

whole can be debated, but in any case, it shows that researchers are moving steadily forward (Shuttleworth and Meekosha 2017).

Towards the end of 1960, the organizations of persons with disabilities began to formulate a new conceptualization of disability as a whole. It reflected the relationship between the limitations that these people experienced, the design and the structure of their environment, and the attitude of the general population (WHO, 2001). The relatively new social model is based on a paternalistic and charitable attitude because persons with disabilities have less value than the rest. That is why special education is considered to be one of the best normalization tools for persons with disabilities (Staintion and Mc Donagh, 2001).

The main features of this model have to do with the causes of disabilities. They are not portrayed as religious but social, and the individual limitations of the people are not the problem, but the limitations imposed by society to guarantee the needs. Besides that, people with disability can contribute to society insofar as they are included and accepted socially. In this classification, disability is determined not by the medical condition of a person, but by the physical and social barriers that the environment imposes on them due to their special condition, and that prevent them from integrating properly and functioning skilfully in society (Jones and Sloane, 2012). Therefore, the social approach seeks the adoption of measures that "(i) allow the highest possible level of exercise of the autonomy of the person with disabilities; (ii) ensure participation in all decisions that affect them; (iii) guarantee the adaptation of the needs of the person with disability; and (iv), make the most of the capabilities of the person, thus displacing the concept of disability for functional diversity" (Constitutional Court, Sentence T 427 of 2012, cited in Jones and Sloane, 2012).

The biopsychosocial model - which integrates medical and social models - has gone from disability as deficiency to disability as difference and social recognition. In such a way that this integration has special significance in that it attempts to take the most accurate elements of each model. From the medical model, it takes into account scientific aspects, and from the social model, it seeks the advancement of equal opportunities. Today these models coexist, but are moving towards the rights approach that implies inclusion, that is, the recognition of the diversity of human beings and by consequently overcoming barriers faced by those who have any disability (Connor, and Valle 2017).

The model based on the rights approach determines that disability is of the relationship of an individual with his/her environment, where his/her functionality is directly related to the

adjustments applied to the medium where it unfolds. This means that disability is not in the person that has some limitation, but in the relationship of this person with a medium that can put up barriers and exclude them or, on the contrary, accept them and provide adjustments so that they can function functionally within their physical and social environment (Stainton and Donagh, 2001).

Assistive Technologies

Intertwined with the larger history of disabilities is the history of assistive technologies that are designed to help accommodate the needs of persons with disabilities. While this was initially restricted mostly to canes, crutches, spectacles, etc., the computer age is greatly expanding what can be done for persons with disabilities. Advances ranging from electronic hearing aids to electric wheelchairs, to communications technology have completely changed the landscape for persons with disabilities.

Although, in true sense, the way to it far and long, one possibility that is becoming more realistic with each passing year is the idea of the *cyborg*, or of a person so intertwined with their prosthetics that they could be considered part machine. Artificial limbs have become advanced enough that South African runner Leonard Carl Pistorius, using two prosthetic legs, became a real threat to the able-bodied runners so much that the rules and regulations had to change (Reddy, 2011).

The cyborg approach brings further complications into the idea of ‘normalization’ as well. If we develop the technology necessary to ‘normalize’ all persons with disabilities, then what exactly stops us there? Many works of science fiction have already explored the possibility of prosthetics so advanced in their design and usefulness that even fully healthy individuals would make a conscious decision between having their whole organic bodies or becoming cyborgs. In that case, a question is raised as to whether a fully organic body, thus unable to perform the actions of a cyborg, becomes the new disabled. This is, thankfully, one philosophical impasse that we can save for some time in the not-too-distant future.

It should be noted that the models used for disability are also a fluid part of the concept’s history. Half-hearted attempts have been made to relegate the entirety of the disabled experience to one concept or another, including divine punishment, personal tragedy, medical problems, social constructs, and so on. Each has been criticized for different reasons and experts now debate how many degrees of separation disability should receive from similar

terms such as impairment. In India the medical model tends to be favored, though a shift towards a more holistic approach is taking place. Unfortunately, no model has ever been capable of encompassing the full scope of individual experiences, often leading to inadequate policies that can only offer blanket solutions, and India has not been exempt from this dilemma (Ghosh, 2012).

The issues surrounding disability will undoubtedly continue to become more complicated and nuanced as we advance further in technology and medicine. This may very well be the biggest barrier that pragmatists face in attempting to offer meaningful solutions to the often-invisible discrimination that persons with disabilities face. In the rapidly evolving computer age, the disabilities that are the most and least serious are constantly shifting as new technologies evolve. We face an unprecedented challenge in keeping global policy up-to-date, in line with this forward momentum, especially when it is generally agreed upon that we are still already behind the point that our policies and systems should probably be able to handle in this day and age.

Disability implies a physical or mental impairment and can be the consequence of a bodily defect, an intellectual limitation or a disorder that prevents or limits an individual to perform certain activities. The World Health Organization (WHO) estimates that more than 1 billion people (15% of the world's population) have some type of disability. 80% of the disabled population live in developing countries (WHO, 2020). According to the Institute of Statistics, in India there are 57,40,000 people with some type of disability, of which almost half (48%) are over 60 years old and only 9% are under 15 years old. 16% have a disability from birth, 39% as a result of illness, 23% due to advanced age, and 15% due to an accident (WHO, 2020)

Persons with disabilities are at greater risk of falling into poverty due to lack of job opportunities, difficulty in carrying out activities, limited mobility, and discrimination, among others. They may experience violations of their dignity or autonomy. They may even find themselves interned in institutions against their will or there may be no infrastructure for them to use public transportation or access public property. In addition to facing these issues, persons with disabilities face economic and social barriers. By removing these barriers, persons with disabilities can actively participate in their communities and be productive. In view of this, several countries have signed the 2006 Convention on the Rights of Persons with Disabilities, in which the signatory countries undertake an effort to ensure that disabled persons enjoy all human rights and freedoms.

If the world is intended to be a place for everyone, why aren't efforts made to ensure all can access it? This query, which directly affects many social groups and particularly those with disabilities, exposes the discrimination they face. This ranges from the job and educational prospects available to them, to the infrastructure of cities in which they live, and varies depending on the region and the people inhabiting it.

Disability and Identity

Identity discourse in disability studies brought out socio-cultural constructions on impaired bodies across cultures influencing academic research as well as activism. The 'corporeality turn' in disability discourse provided critical inputs to the policy framework across countries. The relationship between disability and identity, is critical as it is impossible to treat each other mutually exclusive. Regardless of what an individual may choose to expect, it is currently inarguable that "the way in which bodies look and function are significant in informing social interactions" on both ends of the spectrum (Coleman-Fountain, 2012). On one end of the spectrum, we have those who have exceptional functions in some capacity, such as Olympic athletes, while on the other end there are those who suffer from profound disabilities, ambulatory or otherwise.

In both cases, there is a difference in the social identity of the individual. It would be just as problematic to dismiss the accomplishments of the individual at the Olympic level as it would be to dismiss the hardships of those with disabilities, so we are presented with a social dilemma that juxtaposes such extremes with the idea of being "other" to the norm. Ideally the value of the physical body's differences would be reconsidered and recontextualized to fit within a broader definition of a person's value that better takes into account their non-physical traits such as emotional and mental capacity, but these are qualities that are difficult to assess and quantify, especially on a first impression. The first thing a person knows about someone is generally their physical appearance, and this is not the truth that we can readily dismantle in real world application. Even responses that are intended to be positive could be unconsciously motivated by pity rather than empathy, which only furthers a narrative in which a person with a disability is in some way lesser than an able-bodied individual. These dynamics are difficult to unpack, and the solutions difficult to quantify, especially since the preferences of the individual in how they would like to be treated may differ.

Additionally, the necessary assistance that persons with disabilities must employ, be it through assistive technologies or other means, can enhance the sense of "otherness" that is assigned to

them. While this difference is immediately apparent in the physical presence of aids such as glasses, crutches, or wheelchairs, there are also more niche examples that only affect certain subgroups. Coleman-Fountain references one particular example in the presence of a classroom assistant, assigned to help a student with disabilities. Despite the tangible necessity of assistance, "a classroom assistant can become a factor in the production of othering" (Coleman-Fountain, 2012). The study goes on to argue that the real impact could only be understood by researching the dynamics of the classroom space, including verbal and physical interactions.

There is also the issue of self-identity to be addressed. Being labeled as disabled, specifically by outside forces such as society or peers, "limits opportunity for self-discovery of identity" (Johnstone, 2004). A person who is seen initially as disabled may struggle to assert any identity other than disabled in social contexts, which can lead to feelings of disempowerment. Johnstone goes on to posit that those with disabilities may try to overcompensate for their disabilities, leading to unhealthy mindsets of perfectionism or obsession.

This perfectionism may potentially lead to temporary relief, but it is ultimately a coping mechanism which individuals may feel driven toward "as a means of overcoming [their] distaste for [their] disabled identity" (Johnstone, 2004). As a result, a person may lose months or even years of their life struggling to create an identity other than "disabled." This is all time that an "able" individual is not required to invest in themselves, as ability is only seen as one facet of identity anywhere other than the two extremes of the spectrum mentioned previously (extreme ability and extreme disability).

One of the ultimate goals of disability studies, on a surface level analysis, should be to help persons with disability to achieve a certain level of independence through the spread of awareness, information, and proposals. However, one unfortunate reality of the situation is that most of these proposals lean heavily on systems that inherently cannot provide independence. This is, in part, because "disabled people are uniquely vulnerable to the control of disciplinary mechanisms through their dependence on medical care and intervention" (Anders, 2013). Most of these proposals and measures taken for change must inherently go through authoritative systems such as medical institutions and local governments, forcing those with disabilities to, in effect, ask for permission to pursue change.

Anders (2013) paints a particularly unflattering image of the state of affairs for those with disabilities, pointing out that many of the systems and structures that must be appealed to for widespread change are the selfsame systems and structures that enforced a suboptimal

environment for persons with disabilities in the first place. While his is an unusually bleak assessment of society, it does warrant mentioning that a dependency on solutions set at the institutional level may be inherently problematic if those solutions do not promote the importance of the individual and, thus, the individual's needs.

This is also a point in favor of programs that focus on awareness and education. While enforced material assistance is a necessary and key factor in the furthering of disability rights, a tighter focus on recontextualizing disability at a social level by educating the current and next generation on disability studies could go a long way toward eventual solutions that go beyond those that are institutionally mandated. Change should ideally come from the combined efforts of entire communities who have a sense of responsibility toward their peers, so that government intervention can be targeted toward those projects that can only be completed with the cooperation of those in leadership positions, such as medical reform.

All of these facets of disability and identity are only further complicated when we pull away from the generalized perspective and focus in on the individual. When addressing the needs of persons with disabilities in general it becomes easy to only propose the obvious solutions, such as awareness programs, improved systems for the distribution of assistive technologies, etc. However, this does not inherently address the holistic needs of the individual.

As an example, how would making wheelchairs more accessible or increasing the prevalence of disability studies in schools benefit a woman or child whose rights are being violated at home by an abusive caretaker? How does improving the efficacy of the medical system so that it can better accommodate all patients with disabilities assist an individual who do not have local access to hospital facilities? Domestic violence and lack of medical facilities are problems that affect even able-bodied individuals, but when combined with the dependencies that a person with disabilities may be subjected to simply by virtue of having disabilities, these become problems that are even more difficult to report and address.

Additionally, the individual's needs as a member of other sub-categories of identity may go unaddressed in the interim. Ranjita Dawn (2014) reminds us that "women with disabilities are often seen as asexual". They are perceived as unable to perform the tasks commonly associated with their assigned gender role, such as household chores and child rearing, and are thus relegated to a lesser identity of "disabled" with no recognition of any other identity they could or would embody beyond that. This over-simplification of a person's identity is compounded

with their dependencies to further disempower them, often leaving them unable or unwilling to pursue assistance with problems such as physical or emotional abuse.

On the top of abuse, specifically, communication is an issue. A "major hurdle lies in the ability to communicate what has occurred" due to the lack of access to persons with disabilities (Dawn, 2014). The workers may lack the necessary skills to assist with a specific case, the facility itself may not be handicap-accessible, or there may be problematic social structures in place that limit the impact of such programs, such as when a predominantly patriarchal family refuses to assist one of its members if they feel the need to act in deference to a key member of the family.

The complications that tie disability and identity together are virtually endless, and so it is difficult to draw the line between solving problems of identity and solving problems of disability, since the two factors have very little exclusivity to one another unless you adhere strictly to a medical model (which has its own share of issues). However, the key point of this section is exactly that the two are inextricable. Personal identity must always be taken into consideration when discussing disability and potential resolutions, since the social stigma is inherently part and parcel of the disability itself until such time as we find ways to reduce the correlations between physical ability and social acceptance.

Disability, Gender and Sexuality

One recurring issue with disabilities, both in representation and in social progress, is with regard to its complicated relationship with gender and other marginalized communities. Here, gender is used as an example of the relationship that disability has with other disadvantaged demographics, while sexuality is used to explore the way that disability and other minority groups tend to be used interchangeably in literary and social constructs.

Mehrotra (2006) reports specific details about the lives of nine particular women with disabilities, in an attempt to better build the narrative of the women who suffer from disabilities. In general, the anecdotes reveal that the families of the women were often hesitant or financially unable to pursue medical treatments. Mehrotra (2006) also observes that women with disabilities tend to rely heavily on the support of other women family members, particularly sisters, to the extent that many disabled women are married into the same households as their sisters. Some parents of disabled women report paying heavy dowry due to disability. Also, women with disabilities are often found to have a more balanced workload within the family

home they're born into than in their married homes, where the woman of the house is expected to be responsible for all of the housework by default.

There is also a clear class disparity in how problematic a disability for a woman. Brahmin women tend to be free from agricultural labour, giving them a distinct advantage since household chores are usually easier to handle with a disability than agricultural labour. Jat and Yadav women, in contrast, face greater discrimination due to their inability to contribute to agricultural labour. Young girls with sensory disorders tend to face less functional obstacles in their lifestyle than those with severe mobility issues. In India, pressure to care for a disabled girl in the family often falls squarely on the mother, thus leading to a gender-isolated experience for much of the personal life. Men in rural India tend to avoid caring for their disabled daughters as much as possible, largely to avoid drawing attention to a disabled in the family, which can naturally lead to lopsided and incomplete care (Ghosh and Banerjee, 2017).

In an ethnographic study, Nandini Ghosh exploring the relationship between gendered identities and disabilities in Bengal found that most of the participants saw their gender role as given, and viewed disability as impairing their ability to perform that role. She further concluded, from her interviews, that the degree to which the disabled interviewees felt impaired or persecuted differed greatly depending on nuances of their socio-cultural positions and the severity of the disability. Additionally, the study found that many disabled women simply did not recognize their situations as unusual in the way that an onlooker would (Ghosh, 2012).

One reason that women with disabilities require more public representation than they have now is that they often face completely different standards and limitations compared to women without disabilities. Women with disabilities are often not seen as women by an able-bodied society who sees them only as disabled. As a result, many beauty standards and marriage standards simply apply differently or even not at all. The feminist movement assumes inclusion of disabled women among their numbers, under the blanket notion of "all women", but neither the feminist movement nor the disability rights movement fully encompasses the needs of women with disabilities (Ghai, 2015).

While disabled women may not always face the same marriage expectations and beauty standards as their able-bodied peers, there is a significantly increased risk of violence and rape for disabled women. This issue may fall by the wayside if rights movements do not actively try to provide room at their discussions for women with disabilities. Indians, in particular, place a heavy emphasis on getting their daughters married- disabled or otherwise, as it is often seen as

the final responsibility of the parents in providing for their daughter's future. Parents may settle for a less appealing marriage prospect than they would otherwise, even if it means paying substantial dowry or sending their daughter off to be a second wife, all in the interest of seeing their daughter married at any cost. These marriages often prove to be shakier and less fulfilling for both parties involved as a result (Reddy, 2011).

This, in turn, skews the statistics of women with disabilities who face domestic abuse. Due to the perceived notion that they were a burden the husband was paid to accept, women with disabilities may find themselves in extremely uncomfortable, inappropriate, or even wholly dangerous home settings. Her parents may have a certain amount of room to intervene, but a woman's fate in India is tied inextricably to the capacities of the husband, who may in turn have some sort of personality defect or substantial personal failing that would have already been problematic in an ordinary marriage.

In India, disabled women face double discrimination as the traditional roles for a woman to play in social settings are radically strict (Mehrotra, 2006). A disabled woman is seen as unable to fulfill the role of a woman properly. Physical disabilities, in particular, imply that she will not be able to do housework or raise children with the same level of ability as a non-disabled woman, and this is used as a mark against her individual worth.

An Indian woman born with one or more disability conditions faces the highest level of misfortune. She now has to contend with being a daughter, in a culture where a son would have been more advantageous, with additional permanent disadvantages that come with being disabled. As such, her position within the family is of one who is seen as actively diverting their resources instead of contributing to them. She is also less free to resist arranged marriage than an able-bodied woman, unless she comes from a wealthier background (Ghai, 2002). This is further compounded by the superstitious beliefs that a daughter with a disability might represent divine punishment, either for a past life or for the sins of the family.

One of the most serious side effects of these multiplicative disadvantages is that many solutions which were already tenuous at best become even worse. A program that is designed to address the needs of able-bodied women may not address the needs of women with disabilities. Similarly, a policy that is enacted to benefit persons with disabilities may be tilted in favor of benefitting primarily men with disabilities. The complications that can arise from being entangled in multiple disadvantaged groups as a single person are not to be underestimated.

Meanwhile a disabled son, while still disadvantaged in many ways, is not seen as nearly as crippling to the family dynamic. As such disabled men are still allowed to seek able-bodied or "normal" women just as able-bodied men do, further devaluing an already marginalized group (Ghai ,2002). The irony of this situation is that the man's place in the household is so significant in Indian culture, that an able-bodied woman married to him nearly becomes disabled by proxy. She will naturally be expected to act as the primary caregiver for her disabled husband in the event that he is unable to perform any daily activities, often while still dealing with a societal pressure to please her in-laws and fill out her daily chores. The husband, despite disability, may ultimately find himself with more freedom in his life and personal affairs than his chronically overworked wife, when the inverse would almost never be true.

Additionally, India is already numb to the widespread practice of aborting female fetuses. The male to female ratio in the country has only become more skewed in recent years, with the advent of technologies that can accurately reveal a gender pre-birth. This numbness spills into any reason to abort an "undesirable" fetus, including disabilities and birth defects (Ghai 2002,). This in turn increases the disparity of treatment between able-bodied and disabled persons over time, as the common logic turns from "it could not be helped" to "why did you keep it?". The practice of fetal abortion represents a sort of quiet crisis as society continues to treat elimination as a favorable option in lieu of simply raising a child with a disability.

A woman with disabilities often has sparser marriage options and motherhood opportunities when compared to her able-bodied peers, as well. There is additionally a misconception that disabilities will inevitably be passed down to her children. The social biases regarding what a woman should be in Indian culture match up poorly with the conception that the general public has regarding disabled persons. Women with disabilities thus face more frequent divorce and abandonment than able-bodied women (Mehrotra,2006). These acts of abandonment are especially concerning as, depending on the severity of the disability, the woman may find herself in a genuinely life-threatening situation in a worst-case scenario. Having already paid dowry and dealt with the realities of marriage once, only to be abandoned at an older age with even less prospects, the victims of such divorces are then subject to the whims and efforts of relatives and local services.

It should be noted that the degree to which a disabled woman suffers does vary widely depending on her family situation, the age at which she acquires a disability, and various other factors. As such, there is no one over-arching correct answer to how to best improve the

situation, but it stands to reason that, cultures wherein gender roles are strictly defined will continue to provide unique problems for disabled women. Just as disability has been seen as a pathological issue in many points across history, homosexuality has been called a disease, a deviance, and has faced similar criticisms to disability in terms of religion and public perception. Unfortunately, this underlines one of the key issues that all disadvantaged parties face in that they are often compared to each other and used metaphorically to represent each other (McRuer, 2003).

The problems that arise from these metaphorical relationships are multi-faceted and complex, because they reduce all minorities to simply being one vague contiguous 'other' when they each need to be examined independently in order to make any real progress toward a more modern understanding of human relationships. For every time that a rights movement takes inspiration from another rights movement, there will also be a time that multiple movements are discarded simultaneously, under the guise that the bulk entirety of those rights movements represents an unlikable 'other' in society. It is in this complicated coupling of issues such as feminism, gay rights, and disability rights that we start to see muddled interpretations that do not represent the independent needs of a particular demographic, so much as a mixing of the facts that may or may not end up accurately translating parts of the whole. Persons with disabilities are at a special risk in this scenario, as their needs are often greater than simply being 'treated as equal.' Respecting a person with disabilities is a positive attitude, but it means nothing if that respect does not build an accessible ramp in front of the city bank, or bring awareness in some meaningful way.

These are, of course, only a few of the many marginalized groups that a disabled person can fall under. Persons with disabilities can be of any race, class, sexuality, gender, religion, etc. This can result in an individual easily falling into two or more marginalized identities at the same time. Any person can develop a disability at any point in time, so it is important to recognize that a person with a disability does not only face the problems intrinsic to the disability. While social change may appear to be slow and gradual, it should be remembered that each favorable change affects more than just one demographic, due to the significant overlaps between marginalized groups.

To put it more simply, a policy that improves the lives of persons with disabilities takes some of the weight off of women with disabilities, POC (Point of Care) with disabilities, impoverished persons with disabilities, homosexuals with disabilities, etc. These are all people

who face complicated forms of discrimination in both personal and institutional settings, so every step taken to ease their burdens will ultimately have a more far-reaching impact than it would seem to at first glance.

Coping mechanisms adopted by Persons with Disabilities

Denial: Some individuals attempt to reject the reality of their disabilities, managing them in such a way as to make them appear insignificant. This can be done by actively avoiding the situations which highlight their impairment, or by relying on the support of others to conceal it. Additionally, those with speech impairments may take extra measures to mask their defect by avoiding speaking to strangers or words which are harder to pronounce. Despite these attempts, they may still feel the need to deny and distance themselves from the stigma associated with their disability. Denial is unlikely to subside as a coping mechanism for persons with disabilities until the stigmas associated with disabilities have been alleviated. It may be possible to decrease instances of denial by increasing access to educational materials regarding disabilities, increasing awareness of the issues that persons with disabilities face, and improving the public image of disabilities as a naturally occurring difference.

Normalization: The incapacity is integrated into the daily life of the disabled, becoming a habitual and accepted part of their experience. This does not mean the goal is to make them like everyone else; rather, it enables them to lead their lives as normally as possible, with society providing consistent assistance and conditions. Whether this pattern is problematic or not is up to interpretation, since it largely depends on how accessible society is to the individual. If living in an extremely accessible society, then normalization might not be a significant problem. In cases where the subject faces heavy resistance from the surrounding society, it could constitute a grey area that borders on denial.

Withdrawal: The disabled often distance themselves from social groups and wider society, a pattern that is reflected in institutional responses. Not only are disabled people often placed in institutions, resulting in their exclusion from the greater community, but they can also become even more isolated and withdrawn while inside these settings. Disengagement is problematic as it leads to a silent minority, especially in the case of disabilities. Persons with disabilities do not often have access to a receptive community of like-minded individuals, as is the case with a caste, race, or gender. As such, withdrawal can be analogous to a social death of the individual, leaving their voice unheard.

Resistance: One can use their disability to actively advocate for both personal betterment as well as wider social change. This may be done in small but meaningful ways such as rebelling and resisting, and should be seen as part of a larger collective effort. (Park, 2007 cited in Plummer and Macionis (ed.), 2016).

The Disability Rights Movement

The Disability Rights Movement is a global phenomenon which is becoming increasingly influential for people with disabilities. Organizations like Disabled People's International, the Global Deaf Federation and the World Blind Movement are prominent at both a national and international level. Through this movement, disabled people are empowered and given a platform to challenge the preconceived notions and stereotypes associated with disabilities, and to make autonomous decisions about their lives. The Disability Rights Movement is representative of the new social movements that are reshaping identities and society as a whole, enabling a heightened political awareness in a post-industrial world.

According to Mike Oliver there are three main kinds of disability organizations:

Coordinating Organizations: The Umbrella is the United Kingdom's nationally recognized representation of the global Disabled People's Movement. Established in 1981 by disabled people in order to encourage full incorporation and involvement in British society, it now speaks for about seventy organizations of disabled persons across the United Kingdom at the national level. These groups have a collective membership of approximately 350,000 disabled people, and The Umbrella offers support to them, works to address issues with a human rights-based approach, and believes that they were instrumental in bringing about the Disability Discrimination Act. As one of the oldest and most well-established organizations in the field, it formerly had close ties to charitable bodies and provided a variety of consultations and services. However, this has altered significantly in recent years, as The Umbrella has become increasingly devoted to grassroots activism.

Self-Help: The 'Independent Living Movement' (De Jong, 1979, cited in Macionis and Plummer, 2016) is an illustration of self-help organizations that experienced a significant shift from a bio-medical perspective of disability to a social model concept during the 1970s. The objectives changed from the cure, maintenance, and protection of disabled individuals (who were viewed as having an infantile reliance) to aims of full involvement and inclusion within society. This movement arose in North America in tandem with other counter-cultural groups

of the late 1960s, such as the women's, black, gay, and student movements, and had been previously established in Scandinavian countries during the 1970s.

The disabled role and its associated stereotypes are now being challenged. The focus has shifted to the normalization, mainstreaming, and deinstitutionalization of the disabled. Over the past 40 years, many of these ideas have become widely accepted. Today, most Western governments seek to include the perspectives of disabled people in their policies and programs. Independent living centers are run by disabled people and often exceed expectations. Additionally, various organizations have been set up to advocate for the rights of disabled people and to promote changes in transport systems, restroom facilities, recreation, shopping, education, employment, and more.

Populist/Activist: In the United Kingdom, disability activism has become increasingly influential in the last few decades, particularly in the 1970s with the formation of UPIAS - the Union of Physically Impaired Against Segregation. This network of activists is renowned for its 'in your face' approach to direct political action and raising awareness of the issues faced by disabled people. Consequently, this movement has played a major role in the creation and implementation of legislation and policies which aim to improve the lives of disabled individuals.

Activist groups are typically the most progressive of the organizations. They routinely provide a comprehensive assessment of disability politics and initiate intense conversations about the destiny of disability. Not only do they critique the reactions to disability, but they also deem the general society inadequate. Disability identity politics offer an alternative.

It should be noted that the efforts of the disability rights movement are not infallible. Across multiple countries, voices that speak about disability are usually heavily biased to favor disabled persons who are male and who are of working age. All other demographics tend to be treated as an afterthought, creating a rift between the goals of the movement and the needs of disabled persons in general (Ghai, 2015).

Also, as noted previously, it is highly likely that those persons with disabilities who have less severe issues with their daily functions will be given a disproportionate voice within their respective organizations. This is not due to any particular bias of the society, but rather a construct of circumstance. Because people with mild disabilities have more freedom of

movement and more opportunities to leave their homes and lead independent lives, they will naturally be put into positions that make them freer to vocalize their thoughts.

A similar issue arises in caregivers who may stand in for their disabled relatives. In the event that a caregiver is given free room to speak, it is not unthinkable that they would place an emphasis on demanding more rights and resources for other caregivers like themselves. While this is not intrinsically harmful, it can occasionally lead to resources being funneled away from the actual persons with disabilities in favor of putting those resources in the hands of their caregivers, who may or may not actually have their best interests at heart, since the relationships between individuals are naturally prone to much variation.

Additional biases emerge to favor those in positions of relative power, such as the wealthy or politically educated. Since education and capital are rarely equally distributed across demographics, there is a divide between how the needs of a wealthy educated disabled person and the needs of an impoverished uneducated disabled person are seen. This difference in visibility contributes to a difference in treatments, leaving the impoverished person(s) at a significantly greater state of disadvantage.

Disability is a human development issue, because it has a direct dualistic relationship with poverty. The correlation between disability and poverty is strong, with a heightened risk of poverty being associated with disability, as well as a greater likelihood of disability occurring in those who are impoverished.

The Disability Rights Movement in the West

There are several international documents that have highlighted disability as a matter of human rights, among which include the Action Program Tourney for People with Disabilities (1982), The Convention on the Rights of the Kid (1989), and the Standard Rules on the Equal Opportunities for People with Disabilities (1993). Around 40 countries have laws against discrimination that were passed within the 1990s (Emmett, 2006).

The Convention on the Rights of Persons with Disabilities (CRPD) applies the rights approach, emphasizing that general human rights and rights specific to persons with disabilities should be the focal points. Even in countries where the CRPD is not ratified, there may be significant influence on other human rights conventions relevant to that state (Thomas; 2005).

Disability Policy Frameworks in India

India is a part of what Meekosha and Soldatic call the 'Global South,' encompassing a large number of nations which are forced to rely heavily on research conducted by experts from the 'Global North'. This can lead to legislature based on incomplete or inaccurate data, as the voices of local disabled persons are not always being represented properly by these foreign studies. (Meekosha and Soldatic, 2011). However, the literature on the experience of disabled persons in India is steadily growing.

"Divyang" is a Hindi word that attempts to denote disability with a more positive connotation. It is a qualifier that reflects the conviction that people with a disability develop another greater capacity in other facets. However, the reality has been audited by the study "Accessible India", carried out by the Geographical Society of the Indies together with the State Representative Platform of People with Physical Disabilities. The report, which was presented in Madrid, audited *in situ* some of the most representative hotels and monuments in the country to check if tourism is accessible in India (http://disabilityaffairs.gov.in).

The result of the study is a report of the three cities of the golden triangle of the country - Delhi, Agra and Jaipur - documented in accessibility. And it is above all a practical guide for travelers with reduced mobility that compiles the hotels and tourist monuments that comply with the predefined standards and in which the degree of accessibility of the hotel facilities, transport or access to the facilities is specified. Among the jewels that have been audited are some World Heritage Sites, such as Qutub Minar, Humayun tomb of Delhi, the Jantar Mantar astronomical observatory in Jaipur; the imposing Jama Masjid Mosque in Delhi; the Red Fort of Agra with its views of the Yamuna River and the Taj Mahal. And of course, the Taj Mahal itself. And among the hotels there are some of the main luxury hotel chains in the country such as the Oberoi, The Lalit Hotels, or the Radissons. While inclusive tourism remains a pending issue in almost all countries, the Government of India is making constant efforts to promote making the country more accessible (http://disabilityaffairs.gov.in).

The Constitution of India guarantees freedom, justice and equality for all individuals, including persons with disabilities, and lays the foundation for an inclusive society. In its preamble, it states that India will ensure that all its citizens enjoy "social, economic and political justice, freedom of thought, expression, belief, worship, and equal status and opportunities."

- It acknowledges the requirement of implementing special strategies to ensure persons with disabilities are able to take advantage of all human rights and fundamental freedoms, and have a dignified life, deprived of violence, mistreatment, disparity, poverty, or exclusion.
- The Government, adhering to the United Nations Convention on the Rights of Persons with Disabilities, passed the 2016 Law on the Rights of Persons with Disabilities, which grants numerous rights to individuals with disabilities. Furthermore, the Law requires that state governments and local authorities take action to guarantee that persons with disabilities are able to access the same privileges as those without disabilities. On January 4, 2018, the Government notified the adoption of guidelines to assess the degree of disability of a person, applicable uniformly throughout the country.
- In addition, from 2016-2017, the Government has started the unique disability identification project to create a national database of persons with disabilities and issue an identity card stating the disability (UDID). The database will provide an online platform for issuing disability certificates in accordance with the assessment guidelines. The project has begun to be applied in 29 states and territories of the Union. In the course of the current year its application will be extended to all the states and territories of the Union that include all the districts of the country. The identity card for persons with disabilities will be interoperable between states and valid throughout the country.
- India has launched a strong affirmative action program to ensure substantive equality for all. Article 15 of the Constitution of India prohibits discrimination on the grounds of religion, race, caste, sex or workplace. However, the Constitution allows the State to adopt special provisions for the advancement of the backward classes from the social and educational point of view, as well as in favor of the registered castes and tribes.
- The Government has notified the Regulations on Persons with Disabilities, of 2017, to ensure that article 3, paragraph 3 of the Law of Rights of Persons with Disabilities, of 2016, is effectively applied without harming these persons. In accordance with the Regulations, the heads of the establishments shall ensure that this safeguard provision of the Law is not used improperly to deny any rights or benefits to persons with disabilities.
- The 2016 Law on the Rights of Persons with Disabilities recognizes the particular needs of women with disabilities, requiring Government and local authorities to take action

to ensure that women and children with disabilities are able to enjoy their rights to the same degree as all other individuals.

- Under the Law, women, particularly those with disabilities, must have access to appropriate information on reproductive health and family planning. In accordance with its provisions, no woman with a disability shall be subjected to any medical procedure without her express and informed consent.
- The Law establishes that at least five women be appointed to represent persons with disabilities to serve on the Central Advisory Council on Disability. Thus, five women have been appointed as members of this Council, established by the Government on November 8, 2017, representing non-governmental organizations (NGOs) in charge of disability issues or organizations of persons with disabilities.
- Under the Act, the Government will formulate plans and programs to provide social security measures for persons with disabilities, which, inter alia, include support for disabled women to obtain livelihoods and raise their children.
- The Law on the Rights of Persons with Disabilities provides that children with disabilities have the right to live with their parents. In exceptional cases, when parents are unable to care for their disabled child, community rehabilitation may be used in a family setting or in a foster home run by the Government or NGO.
- The Law on the Rights of Persons with Disabilities contains explicit provisions on raising awareness of the rights of these people. Provides that the Chief Commissioner or the state commissioners organize, encourage, support and promote awareness campaigns and programs among the main stakeholders to protect the rights of persons with disabilities.
- It provides orientation and awareness activities for schools, high schools, universities and professional training, as well as for employers, administrators and collaborators, regarding the rights of persons with disabilities.
- The Central Advisory Council on Disability practices systematic coordination with all relevant line ministries and departments. Its detailed program is distributed to all central ministries and departments, which is then discussed in meetings. The department that acts as the secretariat of the Central Advisory Council deals separately with matters pertinent to any sector with the competent department or sector ministry. Similarly, matters pertaining to the states are discussed with the corresponding states or Union

territories (Ministry of Social Justice and Empowerment, Department of empowerment of Persons with Disabilities retrieved from, http://www. disability affairs.gov.in).

Demographics of Disabled Population in India from Census of India

Disability data for India has been collected in some form or another since the Indian Census of 1872, but it is generally agreed that the numbers had always under-represented the actual number of persons with disabilities. This was considered a concern as early as 1931, when the Census Commissioner publicly noted the problem. Perhaps partially due to these issues, the practice was discontinued that same year. In these early census reports the term *infirm* was used. In 1981, during the International Year of the Disabled established by the United Nations, disability was once again a point of interest for the Indian Census. This time the terms completely deaf, completely crippled, and completely blind appeared on the census. Unfortunately, concerns were raised once again about the reliability of these numbers in a country which heavily stigmatizes disability. The matter was dropped from the census again in 1991 (Reddy and Sree, 2015).

Disability rights groups, NGOs, and civil rights organizations have since contributed heavily to the revival of disability representation on the census. These groups continued to provide new terminology in order to achieve more accurate enumeration in the 21st century. The 2011 census included vision disabilities (which now includes spectacled persons), speech disabilities, hearing disabilities (which now includes persons with hearing aids), motor disabilities (which now has a much more robust definition compared to 2001), and mental disabilities (which are now divided into mental retardation and mental illness). This was a tremendous step up in representation compared to the terminology used only one decade before (Reddy and Sree, 2015)

Additionally, two ‘catch-all’ terms were used that had not been present before 2011. One was for ‘persons with multiple disabilities’, which enabled the census enumerators to include those under this category who provide incomplete information because of inadequate understanding of their specific disability. The other term, which is a true catch-all term, ‘Other disabilities. This term is vaguely defined resulting in the inclusion of people under this category whoever reported some form of physical inability, accrued even due to aging like joint pains, low vision, etc.

As per Census 2011, in India, out of the 121-crore population, 2.68 crore are 'disabled', amounting to 2.21% of the total population. The results from the Census 2011 reveal that persons with disabilities are spread out across India. Uttar Pradesh accounts for 15.5% of all disabled persons in India. Census 2011 presents that the number of persons with disabilities increased from 2001 to 2011, but it is important to remember that Census 2011 measured eight broader categories of disabilities whereas Census 2001 had only searched for five rather specific disabilities by comparison. Roughly 69.49% of persons with disabilities were confined to rural areas. The distribution of PWDs seemed to be fairly consistent across the different terms used, excepting 'motor disabilities' and 'multiple disabilities' which were far more prevalent in rural areas (Reddy and Sree, 2015).

The Indian Census still faces challenges in collecting accurate data to this day, thanks in large part to the stigma associated with disabilities and the lack of proper education and detailed research into persons with disabilities. Reducing the negative stigmas will take both long stretches of time and a concerted effort by the state. This is not to say, however, that efforts are not already being made. Thanks to the consistent improvements made by concerned organizations and by gradual international influence, the reported numbers do seem to be much more reflective of the reality of disability than they were just a generation ago. Noticeable divides in representation can also give us some insight as to which states and demographics may potentially be under-reporting disabilities on the census. The effort to stretch inclusion by way of expanding the number of categories did, however, seem to have the most noteworthy improvements of all measures taken where representation is concerned.

Having accurate national statistics on the socio-demographic profile of the disabled is crucial in order to identify their needs, as two people with the same disability may face different obstacles in executing certain tasks and have different requirements that necessitate different forms of assistance (Saikia et al, 2016). With comprehensive data and community backing, governments across the world can no longer overlook the countless individuals with disabilities who are deprived of access to health services, rehabilitation, assistance, education, and jobs, and never get the chance to reach their full potential. The benefits of properly educating and supporting persons with disabilities can be found largely in the potential of the individuals who are currently not being utilized to the fullest in a society that does not count them in its calculations.

Conclusion

To summarize the key points of this chapter; disability has emerged as a complex social category in academia resulting in the advancement of disability studies founded on several theories on disability. The general public's perspective on disability has varied widely, and even scholars have been tensely divided between different schools of thought. Having provided brief insights into the historical and social context of disability as a conceptual, methodological and analytical category in this chapter, the next chapter presents a discussion on assistive technology for persons with locomotor disabilities. It discusses the historical and current perspectives on assistive technology, especially in regards to how these technologies are seen by the general public and have been viewed in the past.

CHAPTER 3

Assistive Technology for Persons with Disabilities

Technological advancements in general and assistive technologies for persons with disabilities in particular have occurred more intensely after globalization. Spread of information on assistive technologies and withdrawal of trade restrictions on import of technology and material helped persons with disabilities to aspire for use of assistive technologies in India. Availability of assistive technologies (ATs) within the reach of those who can afford kindled hopes of persons with disabilities to improve their quality of life and overcome the physical limitations due to impairments.

Following the discussion on the conceptualization of disability in Chapter Two, this chapter focuses on the technology question in the lives of the PWDs. It reviews the historical developments in assistive technologies and presents a critical assessment of the Indian context.

Use of assistive technologies is rooted in the basic idea that the lives of persons with disabilities can be improved by appropriate medical intervention through the use of artifacts like prosthetics, orthotics, and several such artifacts for different types of impairments. The idea that quality of life with the use of the ATs by the PWDs is widely promoted by the medical fraternity and adopted by PWDs with the support from the social institutions like family, marriage in the Indian context.

It is imperative to discuss the quality of life of disabled people within the scope of the two mega-models brought up in the prior chapters, i.e., the social and medical models. It was highlighted that there are two distinct interpretations of disability, which has led to two different conceptualizations of this condition. For instance, the medical standpoint focuses on the flawed physicality, while the social model of disability puts emphasis on the social alienation and disgrace faced by those with disabilities.

Health professionals often put forward the notion that technology can be used to ameliorate physical impairments, thereby reinforcing the medical model. Conversely, proponents of the social model contend that society's discriminatory attitudes must be removed for persons with disabilities (PWDs) to experience a quality of life similar to that of the non-disabled. They advocate that PWDs should be able to manage their pain and physical limitations, so as to lead a life no different from that of others. It has been argued that when a normal life is impossible

for persons with impractical bodily conditions, they should be encouraged to use "assistive devices" (Oliver, 1990). Advocates of the medical model maintain that assistive technology is a fundamental medical construct, asserting that those with physical impairments are unable to engage in activities in the same way as those without any such drawbacks. Moreover, they propose that the use of technological aids is no longer an option, but a necessity for individuals with disabilities to be able to participate in everyday life.

The social model of disability disregards any mention of the "quality of life" of those with disabilities. Proponents of the social model initially suggested that the notion of quality of life for the disabled is a fabrication (Oliver, 1990). They argue that the concept is simply a social construct and is used to emphasize the significance of disabled people in society. Michael Oliver (1996) has argued that disability is a socially constructed concept.

Critical Disability Theory (CDT) is rooted in the social model of disability, which holds that the disadvantage experienced by disabled people is caused by a social environment which does not cater to those who do not meet society's standards of 'normalcy'. This concept of equality, which is necessary to meet the political demands of disabled people for inclusion, takes into consideration the fact that differences must sometimes be acknowledged and sometimes ignored in order to promote true equality. CDT celebrates diversity and modifies the idea of equality to incorporate it (Hosking, 2008).

The traditional attitude toward disabled people has been to overlook their voices and disregard their challenges to the mainstream view of disability and their place in society. CDT offers a platform for disabled people to be heard and uses their voices to confront the negative views of disability seen in the media and expressed by the able-bodied. Such views are mirrored in the language used to discuss those with disabilities and their impairments (Hosking, 2008).

Critical disability theory strives to be politically driven, aiming to bring about a shift in society so that disabled people of all varieties can take part in their environment and be fully incorporated into their communities (Hosking, 2008). It provides a system of thought that enables the understanding of the interplay between impairment, disability, and society, and to make sure disability-related issues are taken into consideration in all policy areas.

Assistive Technology - Historical Overview

The history of AT can be divided into the following distinct chronological sections:

a) Pre-modern: Before the 20th century

b) Modern: From about 1900 to the early 1970s

c) Advanced: From 1973 to the present (cited in Saladin, 2004).

Pre-Modern Period

Scherer (1996) draws attention to the crucial distinction between adaptive devices and rehabilitation technology. He characterizes adaptive devices as those that are crafted for the general public yet modified so that they are advantageous for people with disabilities, while rehabilitation technologies are those that augment and aid the rehabilitation procedure of individuals and assist them in carrying on with their daily activities after enduring acute injuries or long-term physical disabilities. Consequently, the origin of assistive technology and the documentation of post-surgical AT to sustain activities of daily living can be traced back to the commencement of AD 600, which is concurrent with the early AT of the Stone Age, which may have included sticks and other natural objects.

Public health campaigns, an increasing awareness of individuals with disabilities, and the invention of Louis Braille's reading method for the blind marked the beginning of the Foundation Period of Assistive Technology (AT). The period following the American Civil War was marked by shifts in public opinion and technological advances, largely catalyzed by returning soldiers who brought a newfound enthusiasm to the creation of wheelchairs and prosthetic devices. These advances enabled individuals with disabilities to survive injuries, engage in activities of daily life, and even educate themselves. Thus, the Foundation Period of AT was a pivotal time, in which early prehistoric documentation to the end of the 19th century, saw the development of a range of tools and devices that have become integral to the lives of those with disabilities.

Modern Period

The move from the pre-modern to the modern era, ranging from 1900 to 1972, was marked by a transformation in thinking with respect to disabilities, transitioning from a medical point of view to a more psychological and social one (Wright, 2000). This shift was further evidenced

by the passage of the Smith-Sears Veterans Rehabilitation Act, P.L. 65-178 (Soldiers Rehabilitation Act of 1918, 40 Stat. 617) in 1918. This legislation marked a significant change in the focus from the disabling condition to the residual functioning of individuals and its associated specific factors. The establishment period brought an increase in momentum that continued until the dawn of the advanced period (cited in Saladin, 2004).

Advanced Period

The Rehabilitation Act of 1973, or Public Law 93-112, was a landmark piece of legislation that marked the start of the period of empowerment for people with disabilities. It stipulated that all children, regardless of disability, should be entitled to a free and appropriate public education. This prompted a surge in the use of Assistive Technology (AT) in schools as they sought to meet the demands of the law. Following this, the Architectural Barriers Act of 1986 and the Technology-Related Assistance for Persons with Disabilities Act of 1988 further addressed the issue of AT for persons with disabilities. Finally, the Individuals with Disabilities Education Act (IDEA) of 1990 reinforced the provisions for AT for students with disabilities.

The Empowerment Period saw a marked rise in the quantity of persons with disabilities and their average life expectancy, largely due to developments in disability and medical research. Therefore, the main focus during this period was on the acquisition of education, the protection of the rights of persons with disabilities, and the ability to participate in society. As a result, persons with disabilities began to benefit from equal rights and obligations as other members of the community.

It is fascinating to note how the notion and execution of technological solutions for functional limitations have progressed over time, becoming more entrenched and celebrated as policies, experiences, practices, projects and mistakes have been continually evaluated and assimilated.

With the gradual growth in the field of assistive technology and the ever-expanding range of inputs, agencies and researchers have suggested categorizing assistive technology products to provide clarity and consistency in communication and interpretation. In accordance with Gitlin's (as cited in Fuhrer, et al., 2003) comprehensive definition, Assistive Technology encompasses a range of elements, including structural modifications (for example, broadening doorways in a residence), special equipment, assistive devices, modifications to non-permanent features of the physical environment, and environmental-based behavior adaptation.

The facts and figures about assistive technology, in both developed and developing countries, help us broaden our perspective on the scope and type of progress it has made in the disability sector and the distance it has to travel to make a more equitable society. According to the 1994 National Center for Health Statistics (NCHS), an estimated 7.4 million people in the US household population used assistive technology devices for mobility problems (as cited in Russell, Hendershot, LeClere, Howie, and Adler, 1997). According to Scherer and Galvin (1996), more people use mobility-related assistive technologies (6.4 million) than any other general type of assistive technology. According to Evans, Neophytou, DeSouza and Frank (2007) the 2000 Audit Commission report estimated that 1.2 million wheelchair users live in England, of which 57,600 are under 19 years of age.

Assistive Technologies in India

The AT scenario in the developing world is considerably more intricate and restrictive. In the Indian context, the available AT database is not very inclusive or reflective of the actual situation. Zutshi (2004) reported that in India, roughly 60% of the disabled are able to function without the help of any aid/gadget, 13% are unable to perform even with the aid of devices and gadgets, and 17% are able to take care of themselves with the assistance of ATs. It also points out that 10% of the disabled have not had the opportunity to try or gain access to aids or devices, consequently making them unable to take care of themselves. Notwithstanding, the share of severely disabled people who are unable to function even with the aid of aids/devices has reduced from 25% in rural areas in 1991 to 13.1% in 2002 and from 20.4% in urban areas in 1991 to 14% in 2002. This demonstrates that the amount of disability has displayed a downward pattern, likely due to the prompt support and medical attention given to the disabled.

It is estimated that about 8 million people need wheelchairs in India (Pearlman, Jefferds, Nagai, Chhabra, and Cooper, 2007). According to 2020 -2021 report of the Ministry of Social Justice and Empowerment of the Government of India, as on 31.12.2021, a total of 5,72,218 devices have been distributed to 1,97,151 beneficiaries in 226 distribution camps. The Scheme is being implemented by Artificial Limbs Manufacturing Corporation of India (ALIMCO), a Public Sector Undertaking under this Ministry from 01.04.2017. A total amount of Rs. 1,212 crores were allocated to the Department of Empowerment of Persons with Disabilities in the financial year 2022-23 (http://www.socialjustice.nic.in, 2021). However, according to the ALIMCO Annual Report 2021-22 production of wheelchairs was only 1,11,667 units. According to the same report, total production of tricycles was 68,005, crutches 72,437, etc. (see Table A).

Considering the lifecycle of a wheelchair, which is estimated to be five years, the number of wheelchairs required would actually be very high.

Table 3.1: Number of Assistive Technology Equipment Produced by ALIMCO in 2021-22

Type of Ats	Number of units
Tricycles	68005
Wheel chairs	111667
Crutches	72437
Prosthetic Upper & Lower Kit and Components	25754
Orthotic Lower Kits and Components	87267
Hearing aids	47347

Source: 49th Annual Report 2021-22 ALIMCO

As per the Country Report submitted by Chaturvedi and Ramesh (2005) based on the Persons with Disabilities in Development India Project, 650 organizations were receiving grants in the form of aid from the Ministry of Social Justice and Empowerment. The low number of NGOs in the disability sector and the lack of coordination within the sector appear to be limiting the effective reach out to the needy PWDs.

Assistive Technology - Models of Practice

Waldron and Layton (2008), in their article, mentioned several published theoretical models of practice applicable to AT interventions. These include:

1. The Bain assistive technology system from Bain and Ledger (1997).

2. Cook and Hussey's (1995) assistive technology model for human activity.

3. Scherer and Galvin's (1996) model of coincident person and technology.

4. Framework for the conceptual modeling of the results of assistive technology devices by Fuhrer, Jutai, Scherer and DeRuyter (2003).

The two most widely recognized AT models are the 'Matching Person and Technology' model and the 'Human Activity Assistive Technology' model (Waldron and Layton, 2008). Despite their differences, all of these models contain the same essential components: the person, the task at hand, the device or intervention, and the environment. Examining these models in a

comprehensive manner highlights the need for a thorough exploration of both the AT user and the technology itself, considering both its hard and soft components, in order to achieve the most effective AT practices.

Matching Person and Technology Model

The Matching Person and Technology (MPT) model (Scherer and Galvin, 1996) and assessment instruments were created to help consumers identify their desired outcomes with regards to perceivable changes in the quality of life, rather than the absence of illness, disability or functional ability. As with other methods, the MPT is a multi-dimensional tool that makes use of the aspects related to the all-encompassing influence on quality of life. The MPT contains three distinct domains, which are the environment, personality, and technology components. The environment component evaluates the characteristics of the environment and the psychosocial realm in which the assistive technology is going to be utilized. The personality component focuses on the temperament and preferences of the individual using the technology. Finally, the technology component encompasses the character traits of the assistive technology itself. Through its multi-dimensional approach, the MPT is able to differentiate the impacts of technology, environment, and personal inclinations.

Human Activity Assistive Technology Model

The Human Activity Assistive Technology (HAAT) model (Cook and Hussey, 1995) is widely recognized as an effective framework for investigating the performance of a human operator in a particular task within a given context. This model was developed by engineers and psychologists to inform the design and implementation of a range of technological developments, such as computers, telecommunications equipment, industrial processes, and vocational tasks. Its utility is particularly apparent in the production of mass-produced devices intended for use by non-disabled individuals. All the models in this framework place emphasis on forming a connection between the person and the technology, with more significant implications than simply using the device.

Assistive Technology - Outcome Measures

For many years, assistive technologies have been employed as integral components in rehabilitation programs around the globe. However, more recently, there has been a surge of

interest in the effects of these technologies. Mobility devices, in particular, offer a variety of possibilities when it comes to physical activity and involvement. Consequently, these are increasingly seen as significant lifestyle choices for recuperation from a variety of ailments. According to Burke and Utley (2013), more research needs to be done to gain a deeper comprehension of the role physical activity plays in aiding mental and emotional healing for those suffering from disability or illness. The existing literature concerning outcome studies of assistive technologies includes a range of topics pertinent to device utilization.

As AT users and providers become increasingly mindful of cost, support systems, and technology abandonment, assessing the impact of AT has become an area of interest. However, the connection between AT and these variables has not yet been studied in depth. Consequently, it is essential to gather a broad spectrum of data coming from the outcomes in order to comprehend the genuine value of the device to the user. The tools to measure different aspects of AT from the user's perspective are few. They are the Psychosocial Impact of Assistive Devices Scale (PIADS) (Day and Jutai, 1996) that measures the user's psychological well-being. The Quebec User Satisfaction Rating Scale with Assistive Technology (QUEST) which assesses user satisfaction with assistive technology devices and related services (Demers, Weiss-Lambrou and Ska, 2002).

The AT Device Predisposition Assessment (ATDPA) likewise evaluates customer contentment with existing successes in multiple functional domains. Moreover, there is an abundance of research that proposes the utilization of other adapted instruments to acquire beneficial data related to device usage, for example the Functional Independence Measure (Keith, Granger, Hamilton and Sherwin, 1987) to evaluate augmentation in health status. The Ladder scale (Andrews, 1976) can be employed to assess the enhancement in satisfaction with life when employing the device.

Smith (1996) indicates that the Assistive Technology Outcome Measurement Project (ATOMS) has identified numerous stakeholders in the AT domain, such as consumers, service providers, developers, researchers, and funders. All of them necessitate more efficient AT result instruments, measurement techniques, and access to outcomes. The primary focus of the whole project is to gain a more comprehensive knowledge of the factors that lead to the abandonment of AT devices and improved performance.

The taxonomy of the Proposed Consortium for Assistive Technology Outcomes Research (CATOR) identified five outcome domains, namely (i) care delivery, which concerns the level

of supervision required by the caregiver; (ii) cost, which pertains to the value of the resources applied to ATD and related services; (iii) residential settings, i.e. the home or a long-term care facility such as a nursing home; (iv) utilization of services, which covers the consumption of resources from the service sector (education, health, vocational, etc.) by means of assistive technology; and (v) device usage, encompassing factors such as frequency of use by individual users, duration of use, and how ATDs are used (i.e. the extent to which they are employed correctly) (Jutai, et al., 2005).

According to Cook and Hussey (2002), user satisfaction is a multifaceted concept that necessitates qualitative assessment. Additionally, universal user satisfaction scales are broad and do not consider the multiple components that determine the utilization or non-utilization of assistive technologies by an individual. In researching the description and evaluation of the usability of AT and its measurement from a human factor point of view, Arthanat et al. (2007) note that generic variables, such as the self-perceived factors of the device, use, abandonment, satisfaction, and wellbeing, are highly complicated. Andrews and Withey (as cited in Brown, Bowling, and Flynn, 2004) suggest that subjective or emotional well-being consists of people's own evaluations of life, either cognitively (e.g., specific or general life satisfaction) or affective (for example, feelings of joy). Self-reported measures of well-being reflect at least four factors: (i) circumstances (ii) aspirations (iii) comparisons with others and (iv) a person's basic happiness or disposition. Self-reported wellness measures consist of an individual assessment of one’s life.

In their research on the taxonomy of assistive technology device (ATD) results, Jutai, et. al. (2005) noted that subjective well-being components are deemed to be the most pertinent for evaluating said results. This construct encompasses both cognitive and affective assessments of how ATDs have impacted someone's life, with the cognitive assessment covering satisfaction and other dimensions like its influence on functional autonomy. Satisfaction has been highlighted as the principal domain of subjective well-being, and users (and their caregivers) may gauge it either in connection to the ATD itself or it effects on certain life domains (as specified by the International Classification of Functioning, Disability and Health) or life in general.

Chase et al. (2000) describes life satisfaction as a psychological state that can be widely associated with psychological well-being. Lund et al. (2007), in a study to determine the relationship between perceived participation, participation problems, and satisfaction with life

in patients with spinal cord injury, found that the domains of perceived participation were all positively correlated with satisfaction with life as a whole, and decreased satisfaction corresponded with a greater number of severe problems reported with participation.

Consumer satisfaction is a result that is critical to measuring the effectiveness of device and service delivery. Knowledge of consumer satisfaction can predict the likelihood of device retention and abandonment. A study by Stickel, Ryan, Rigby, and Jutai (2002) to compare the opinions of users of electronic aids for daily living (EADL), based on interviews twice with an interval of six months, found that consumers, in general, were quite satisfied with the devices and the level of satisfaction remained relatively stable over time.

In a study by Craddock (2006) on students with a variety of disabilities and their subjective preferences reported supportive or non-supportive environments within society. It was found that the non-supportive environments had a negative impact on AT use. A non-responsive environment included issues such as inaccessibility due to lack of ramps or elevators, conference rooms, restrooms, other impassable facilities, and lack of disability awareness among university staff.

In addition to user contentment, quality of life is a significant matter. Brown, et al. (2004) recognize quality of life as an abstract and multi-level notion, typically established by a collection of subjective, social, and financial indicators. It has been operationally defined through measures such as life satisfaction, well-being, adaptive functioning, control of the environment, and socioeconomic indices, however, there is no generally accepted or sanctioned quality-of-life monitoring instrument or theory.

Day, Jutai, and Campbell (2002) stress that the most pivotal view on how an assistive device affects the quality of life is the user's point of view. They posit that the device should foster a positive quality of life, allowing the user to feel capable, self-assured, and motivated to make the most of life's opportunities. Lenker et al. (2005) also emphasize that the impact on quality of life is probably the most significant result from the perspective of the assistive device user. It could be contended that all outcome variables, in fact, reflect some facet of quality of life.

The concept of Quality of Life (QoL), from a perspective of subjective well-being, examines how assistive devices are assessed and their effect on the individual's quality of life. Flanagan (cited in Jutai, et. Al., 2005) outlines the potential in five dimensions: physical and material well-being; relationships with others; social, community, and civic activities; personal

development and fulfillment; and recreation. The evaluation of these five dimensions is used to gauge one's own satisfaction and contentment.

Psychosocial adaptation to disability has been considered to be composed of both global (for example, quality of life) and disability-specific indicators. Jutai and Day (2002), in their study on the description of the Psychosocial Impact Scale of Assistive Devices, defined psychosocial factors as being any factors within the person and their environment that affect psychological adjustments.

In their 2001 study, Day, Jutai, Woolrich, and Strong found that the positive psychosocial impact of wearing glasses was stable. This serves as evidence for the significance of psychosocial factors. Even if the wearer may be content with the glasses' performance, they may still feel displeased with their appearance or the need for regular maintenance, and these feelings can have a detrimental effect on their self-esteem and sense of autonomy. In addition, the user's motivation, desired roles, and the amount of effort they put in to use the glasses must be taken into consideration when assessing the quality of life. Thus, these psychosocial variables are essential in forming a comprehensive understanding of the user's perspective.

In a study, Atherton and Robertson (2006) examined the prevalence of psychological morbidity in patients who had undergone lower limb amputation and used prostheses. All the participants wore prostheses daily. The results indicated that people who showed high public shyness were more likely to be distressed and were more likely to manifest psychosocial adjustment difficulties. This agrees with the theory that the study put forth; people with a high level of public self-awareness are more willing to avoid disapproval and rejection, are more concerned about their physical appearance, and are therefore more likely to be upset if their appearance is not matched conforms to a model endorsed by society.

In their 2007 study of prosthetic amputation, Gallagher et. al. found that people who have experienced limb loss have a series of images associated with them, including the pre-amputation whole body/family body, the traumatized body, the healing body, and the extended body, which is the body supplemented with prosthetic components and mobility aids if necessary.

Psychosocial adaptation to assistive technology can be a lengthy process for healthy populations, due to the emotional adaptation that ensues, which can include the development of a new body image. Hersh (2010) suggests consistently assessing AT products and the

outcomes of their usage by individual and collective end-users. Lupton and Seymour (2000) identified both positive and negative aspects of using the toilet with a mobility device; positive benefits include enhanced movement and socialization, while a negative outcome is the toilet being perceived as a sign of disability, which can distract from the user's individuality. Ultimately, acceptance of mobility devices is obtained by recognizing the necessity of the device, trying it out, and seeing the advantages, like extending the user's freedom and autonomy, as well as protecting their integrity and identity.

Barker, Reid, and Cott (2004) explored the lived experience of stroke survivors who use wheelchairs and identified three categories of wheelchair acceptance: reluctant acceptance, grateful acceptance, and internal acceptance.

Craddock (2006) examined the numerical and qualitative effects of assistive technology on the quality of life, self-worth, and contentment with AT utilization among students with disabilities. A relationship of great dynamism was discovered between the three domains: environment, AT use, and individual characteristics. There was an improvement in the familial and social interactions of the students. They held an optimistic outlook of their worthiness as active members within their relationships and in the world around them, and discovered that they flourished with this supplementary encouragement. A connection between the utilization of technology, temperamental inclinations, personal qualities, and Quality of Life was clearly demonstrated. The pupils' self-confidence grew as they had the facility to showcase their capabilities.

According to Carin-Levy and Jones' (2006) qualitative research, the utilization of wheelchairs was observed to have a positive psychosocial impact. By creating a positive atmosphere, the participants found the activity to be both stimulating and enjoyable, thus leading to an improvement in their quality of life by increasing their social experiences and self-worth, as well as providing them with a sense of equality by being able to partake in the activity as any other individual without a disability.

Amosun, Volmink and Rosin (2005) conducted a study which documented the experiences of undergraduate medical students who were physically confined to wheelchairs, and they discovered that some of the people who interacted with them treated them as if they were distinct, requiring additional care, incapable, and tragic. This consequentially led to feelings of inferiority, which had an adverse effect on their self-esteem. It is believed that people with disabilities encounter multiple psychological, sociological, and environmental hindrances

which can impact their ability to adjust effectively. Wu and Chan (2007) conducted a study to evaluate the psychosocial adjustment patterns of patients with spinal cord injuries, and it was found that there was difficulty in the process of adjustment, particularly in the area of vocational adjustments after returning to their respective communities.

Polgar (2006) asserts that for a device to be considered an effective facilitator of occupation, it must be integrated into the consumer's everyday life. He identifies several factors that can determine whether assistive technology will be a help or a hindrance in occupational performance, which can be divided into two major categories: personal and social/institutional. Among the personal aspects are the user's inclination towards completing a particular task, their attitude towards assistive technology, and any stigma associated with such technology. Social/institutional aspects, on the other hand, encompass the paradox of using tools, the models that shape our understanding of disability, and the impact of people in the individual's social environment, such as healthcare professionals, peers, family, and others.

Polgar (2006) found that the usage of orthodontic appliances and other corrective measures could cause emotional distress in children suffering from cerebral palsy. Many individuals ponder if the benefit of wearing a brace outweighs the negative connotations associated with it. People try to conceal orthotic appliances by donning trousers that extend to their ankles to obscure the brace. Assistive technology can be perceived as a recognition that life has been altered by trauma or prolonged sickness.

The topic of the paradox of technology was brought up, which looked into the disparity between the approval of using technology by people with disabilities and the approval of using technology in the daily lives of those without disabilities. The research indicates that rehab professionals possess expertise in assessments about choosing assistive technology and familiarity with accessible products. Nevertheless, they typically lack familiarity with the usage of assistive devices, thus leaving the ultimate choice up to the individual. The strongest influence on the adoption of AT appears to be the peer group.

Assistive Technology - Factors influencing Device Acceptance and Usage

The perspectives of users with motor disabilities towards AT have been determined to be affected by a number of elements. This psychosocial experience, as perceived by an individual with a motor disability who uses devices, encompasses these factors. To make it simpler to

evaluate and interpret, the various factors have been divided into sociodemographic, condition-specific, and device-specific components.

Socio-Economic Factors

The following paragraphs will discuss the findings and perspectives of researchers regarding the impact of socio-demographic elements on the utilization of assistive technology. These elements are age, gender, type of organization, availability of local support, migration to the facility, social backing, occupation, educational level, life-span, and financial status. Studies have demonstrated that involvement, satisfaction with life, and an individual's subjective experience of enjoying their life are all factors influenced by persons with disabilities.

Berges, Ottenbacher et al. (2006) have determined that an individual's satisfaction is deemed to be a critical factor in the realm of medical rehabilitation. Despite this, their overall conclusion was that sociodemographic characteristics such as age, gender, ethnicity, and marital and socioeconomic status had at best a weak correlation with an individual's satisfaction. Lenker et al. (2005) further suggested that social role performance should be seen as a part of quality of life, and that social role participation measures should encompass activity patterns, residence location, employment, education, general goals of the user, and unmet needs. Consequently, a collaborative discussion between all relevant stakeholders is necessary to identify suitable performance indicators which may differ depending on the use of assistive technology.

Pierce and Hanks (2006) discovered that participation was the most powerful indicator of life satisfaction following traumatic brain injury (TBI), whereas non-participation in activities was the weakest predictor, and body function and structure did not augment the forecast of life contentment. However, community integration, which is a facet of participation, has been observed to bear a demonstrable connection to life satisfaction, although there is some evidence that the quality of social support and changes in psychosocial status may explain the variance in joy with life to a greater degree than community integration by itself.

The functional skills, interests, and family culture of children, in addition to the physical, social, and institutional environment they inhabit, all factor into their ability to participate in society. A greater number of accommodating and hospitable facilities in a community can led to a heightened level of social engagement among children with disabilities. Unfortunately,

attitudinal obstacles and a lack of social support are significant constraints on participation for those with physical impairments (Law, Petrenchik, King and Hurley, 2007).

Raja (2006) found in his study on the utilization of walking aids for children with cerebral palsy in India that the need to walk is a primary concern for these children. Furthermore, it was discovered that recreational activities for those who rely on wheelchairs for mobility are essentially non-existent. Moreover, after a time of regular use, children and their families tend to prefer hand grip aids, as well as the support of furniture and other stationary objects, instead of the suggested devices. This is due to the comfort that they provide as well as the difficulty of transporting walking aids in public spaces.

Nguyen, Page, Aggarwal and Henke (2007) conducted a study that revealed the cultural factors that can shape attitudes and interactions with individuals with disabilities. This can likewise have an effect on the family and communal assistance structures. Such cultural diversities may include religion, education, occupation, and family size and structure, as well as distinct cultures' beliefs concerning health and illness, care for disabled persons, and the costs of institutional and home care. Measuring all the dynamic cultural elements that might be pertinent is an arduous task.

Craddock (2010) conducted a study on high school students in their final year which found that assistive technology was essential for them to successfully pass their second level exams and progress to the next level of education. These students reported that AT gave them the chance to show their capabilities which they had previously been unable to do. Furthermore, they felt that the technology enabled them to work more productively and cover more of the curriculum, thus enabling them to compete equally with their peers in the educational setting.

Regarding socioeconomic status as a factor, Lupton and Seymour (2000) state that the development and commercialization of new technologies are linked to an economy that favors profits, rather than an economy of necessity. These technologies, therefore, are much more accessible to the socioeconomically privileged in society. Aggarwal and others (2005), in their study to develop a new tool to measure socioeconomic status, stated that socioeconomic status influences accessibility, affordability, acceptability, and actual use of various available health facilities.

A study by Ebenso et al. (2007) sought to explore the perception of people affected by leprosy on the impact of socioeconomic rehabilitation (SER) in reducing stigma. The study revealed

that the majority of SER participants reported a variety of improvements. These included: i) personal and family happiness and joy, ii) ability to meet family needs, iii) ability to sustain or manage a business, iv) acceptance and integration, and v) better standard of living. Most of the participants stated that SER improved their dignity to a) acceptance in society, b) the ability to meet family needs, and c) the ability to work like others in society.

Over the past two decades, research into the role of social support in disease prevention and susceptibility has grown dramatically. This has led to numerous studies, from a range of disciplines, that have revealed a strong connection between social support and a range of outcomes that are generally associated with health, happiness, and the ability to cope. Kutner (1987) investigated the use of social ties among people with disabilities and discovered that the majority of the respondents perceived a high level of family support.

In a review of the literature on social support, Chronister, Johnson and Berven (2006) identified three distinct dimensions: structural, functional, and perceptual. The structural dimension examines the connection of an individual to their personal network, analyzing the size, frequency of contacts, composition, density, homogeneity and multiplicity of social ties in the network. The functional dimension encompasses the emotional (showing affection and concern, listening, collaborating on a task), instrumental (providing tangible help, financial and physical assistance), and informative (offering advice, guidance, feedback) elements. Lastly, the perceptual dimension captures the subjective and evaluative appraisal of an individual's social support network.

The utilization of individuals with disabilities is of great significance to contemporary societies (Ville and Winance, 2006). In the rehabilitation sector, work is typically seen as a way to accomplish many of the objectives that deliver personal fulfillment, such as socioeconomic status, interpersonal relationships, psychological well-being, safety, and satisfaction of one's needs.

In 2006, Ville and Winance conducted a study to gain insight into the employment of individuals with significant disabilities who have been confined to a wheelchair. Their findings revealed that engaging in one or more activities is essential for maintaining a healthy mental state, both due to the activity itself and the social interaction typically associated with it. It is widely believed that work, in conjunction with both recreational and social activities, is capable of meeting both objectives. The job must be sufficiently interesting and gratifying to meet a basic threshold.

For some, however, attaining the role of providing care to others is a challenging task, primarily one that deals with one's sense of self-identity. Chase et al (2000) demonstrated that employment had a beneficial effect on life satisfaction. Part-time employees were discovered to have feelings of greater autonomy, experience fewer physical or psychological impairments, and overall greater contentment with life.

Condition-Specific Factors

This examination of literature illustrates the perception and discoveries of the researchers with regards to the impact of a range of condition-specific or clinically-relevant factors on the utilization of assistive technology, taking into account factors such as functional status, the degree of the condition, diagnosis, age at which the condition began, and its duration.

Functional independence, or functional status, is widely seen as an essential goal for AT users, since it is strongly associated with positive functional outcomes and an overall sense of well-being. Lenker et al. (2005) proposed that the domain of functional independence incorporates measures such as discharge destination, functional status, ability, attendance, independence, hours without assistance, and productive activity.

Berges et al. (2006) conducted a study to explore the association between pain and satisfaction with medical rehabilitation. The findings indicated that functional status, as measured by the FIM instrument, was correlated to the patient's satisfaction. This provides a valuable objective tool for rehabilitation service providers to monitor and enhance the satisfaction of their patients. Moreover, it was determined that the optimal point to measure disability is when further functional improvement ceases and a stable state is reached.

Currens and Coats (2000) conducted a study to identify the optimal time for measuring disability following trauma, assessing trauma patients at 3, 6, 12 and 24 months after injury. They suggested that the twelve-month mark should be used as the standard for trauma databases and outcome studies, as it is the point at which patients have reached a steadier state. Pierce and Hanks (2006) then researched the influence of clinical severity on life satisfaction in people with traumatic brain injury, discovering a body of literature that examined the individual and injury-related factors that can affect life satisfaction. However, the results in relation to the effects of initial injury severity on life satisfaction were conflicting, with some studies finding no effect, and others demonstrating the unexpected outcome that greater severity can lead to higher life satisfaction.

Device-Specific Factors

The subsequent paragraphs showcase the researchers' views in regard to the impact of different device-related aspects on the implementation of assistive technology. These device-specific attributes that have been highlighted in the literature on AT services encompass user involvement, the time span of the waiting period, training and maintenance of AT, the content of information and instructions, AT prescription, funding and the frequency of AT use.

The evaluation of AT services must remain a priority in order to ensure that the needs of consumers are being effectively met. According to Sackett (cited in Cook and Hussey, 2002), there are four types of evaluation that should be considered: effectiveness, efficacy, availability, and efficiency. Furthermore, Scherer et al. (2005) observed that the finite resources available to meet the needs of consumers with highly diverse needs necessitates a close match between the AT and the user in order to optimize the efficient use of these resources.

Scherer (1996) argued that while service providers for assistive technology are attentive to the physical needs of those with disabilities, they tend to pay less attention to the psychological and sociological implications of using such devices. If this issue is not explored and addressed, it is unlikely that those with disabilities will be able to achieve a satisfactory quality of life. Jutai, et al. (1996) conducted an investigation to comprehend the role of AT services with regards to overall rehabilitation. They concluded that the provision of AT services should not be treated any differently from other forms of rehabilitation. Service providers of AT often believe that their assistance is highly beneficial to AT users, yet whether they are able to assess the effects of their work will depend on the culture of the institution in which they work, regardless of their personal dedication to the cause. Heaton and Bamford (2001) conducted a study to analyze the outcomes of equipment and accommodations, and discovered a variety of desired effects of service delivery or service process outcomes.

It is essential that users are accorded respect and recognition, and that services that meet and bolster the decisions they have taken (including aspects of culture and faith) are available. User satisfaction is not only contingent upon the efficacy of the services rendered, but is also heavily affected by the manner in which those services are delivered. By properly incorporating the client's experiences and knowledge into the decision-making process and involving him in the selection of devices, the occupational therapist can ensure that the practice is client-centered.

An important theme that emerged in Mortenson and Miller's (2008) exploration of the wheelchair procurement process from the customer's perspective was "who decides?" The customer's level of engagement in the procurement process was delineated by this. According to Scherer et al. (2005), consumers should be given the opportunity to develop a suitable combination of person and technology from the outset and to participate in the choice of assistive technology.

The process of aligning people and technology continues to be convoluted as individuals' anticipations and responses to technologies are intricate. Respondents expressed concern about the possibility of delays. The waiting period between referral and acquisition of equipment is always of paramount significance. For people affected by progressive neurological diseases, any postponement can lead to their medical equipment no longer being of use due to the deterioration of their condition.

Cowan and Turner-Smith (1999) conducted a survey to investigate the experiences of people with physical disabilities and found that the length of time between referral and obtaining an electric wheelchair varied greatly, from a few weeks to four years. Charities have been operating for four months, and two privately funded chairs have been running for three months.

Wilson, McCracken, and Cummings (1999) conducted an audit study on AT waiting time for patients with rheumatic disease over a period of 18 months. The results of the first audit showed an average waiting time of 39 days for an assistive device and the second audit showed a waiting time of 21 days. The Fife Rheumatic Diseases Unit (FRDU) established in 1994 established a three-week standard for the prompt provision of an assistive device as a key component of a patient training program to improve compliance. Polgar (2006) cites Zimmerman who advocated introducing devices early in rehabilitation in order to demonstrate their value to the individual and help them to return to their desired occupations.

Device training and maintenance is an integral part of the provisioning process, as it provides users and caregivers with assurance in the use of the equipment. A survey conducted by Cowan and Turner-Smith (1999) revealed that the instruction given for the operation of electric wheelchairs was inconsistent. The survey participants reported inadequate training, with many not receiving any training at all. Similar findings were reported in a prior survey of wheelchair users. According to Fliess-Douer, Vanlandewijck, and Vander Woude (2013), approximately 80% of individuals with Spinal Cord Injury (SCI) are reliant on a wheelchair for the remainder

of their life, thereby making the acquisition of wheelchair skills a critical component of their SCI rehabilitation.

Riemer-Reiss and Wacker (2000) found in their survey that those with disabilities frequently lack the chance to try out assistive technology devices before they purchase them. In theory and practice, having the opportunity to test the device before buying it has been acknowledged as a successful way of avoiding technology disruption and sustaining its usage. Nonetheless, this has yet to be fully integrated into the distribution of technology to people with disabilities.

Mandelstam (2001) conducted a study on the safe use of equipment for the disabled and manual handling, which reported that risks can be decreased by encouraging patients to report any defects, and through regular inspection of potentially hazardous technology requiring maintenance and sometimes disapproval. Lupton and Seymour (2000) conducted a related exploratory study, the results of which showed that when a technical failure occurs, those with disabilities can find it difficult to address the issue. The breakdown or malfunction of technology can be especially detrimental to those who have worked hard to achieve autonomy, self-control, independence, and a sense of normalcy, as these feelings can be easily disrupted.

Cowan and Turner-Smith (1999) discovered that the availability of information was a matter of concern that could be related to disuse or misuse of equipment. The participants were unaware of who to reach out to in case of an issue or were not able to secure a satisfactory response.

It is imperative that users of ATDs have access to relevant information and directions in order to use them safely. Insufficient data and guidance can render the utilization of these gadgets potentially hazardous. Pain and Wiles (2006) conducted a study to investigate the life experience of disabled people inhabiting the community, and revealed a heterogeneity of access to information regarding assistive technology.

It is usually advisable to seek assistance from a professional as they can be seen as impartial and have the capability to understand the requirements of the individual. Input from corporate spokespersons can be unpredictable and interpreted with the ultimate goal of making a sale. The authors Sprigle, Lenker, and Searcy (2012) distinguished four categories of services: pre-delivery, delivery, post-delivery, and supplementary.

Cook and Hussey (2002) identified the "easy to buy device" factor as an important contributor to the abandonment of the device, as this refers to the situation where a consumer obtains one

from a vendor without an evaluation. Samuelsson and Wressle (2008) found that when the prescriber took into account the user's needs, wishes, and demands, it had a positive impact on the user's satisfaction level. Similarly, Cowan and Turner-Smith (1999) highlighted that the lack of funding was a major issue for respondents, with many having to finance equipment themselves due to the unavailability of funds or failure to supply the item by the services in their area.

Arthanat et al. (2007) asserted that the frequency of use is an observable outcome of usability, comfort, satisfaction, perceived autonomy, and quality of life. Lenker et al. (2005) conducted an analysis of research results and determined that frequency of use is best assessed in terms of days per week or month. Moreover, Cowan and Turner-Smith (1999) found that 94% of the participants in their study used the device daily and only 6% used it infrequently.

Assistive Technology - Retention and Rejection

The use of assistive technology to support persons with disabilities to reach their highest potential and independence has become increasingly accepted. Nevertheless, numerous reports of dissatisfaction and the abandonment of devices point to minimal use of AT among people with physical disabilities. Reports of non-use in the literature vary, but may involve not using the device, not using it full-time, not using it at the time of the study, not using it frequently, low average use, not using it correctly, or not using it for activities (Dijcks et al., 2006; Philips and Zhao, 1993). This is an issue of considerable concern within the AT domain.

The repercussions of abstaining from technology can be significant, leading to a decrease in capabilities, autonomy and freedom, as well as a rise in financial obligations. As the number of those with disabilities, particularly those with more serious disabilities, is on the upswing, these costs can be considerable. Consequently, it is vital to build a further comprehension of the motives and ways in which technology users choose to take up or reject certain devices, so as to more effectively boost the efficiency of assistive technology interventions and increase user satisfaction with devices (Dijcks, et al., 2006; Philips and Zhao, 1993).

In their 2003 review article, Wessels et al. identified a variety of variables that could potentially be responsible for the lack of AT utilization. These could be divided into three categories: environmental, device-related, and user-related. When it comes to user-related factors, age and diagnosis, client and family expectations, and the emotional maturity of the client are all essential elements to consider. Additionally, whether the disability is sudden or gradual, or

congenital, is also a factor to take into account. With respect to device-related aspects, the quality, appearance, availability of choice, portability, weight, ease of use, and the presence of multiple devices are all important criteria. Lastly, environmental factors include social support, the suitability of the physical environment for the device, opportunities for use within the environment, and issues related to the appliance market, such as testing, training, delivery, supply and support.

Biddiss and Chau (2007) illuminated the complex nexus between prosthetic application and rejection, which was demonstrated to be profoundly dependent on the idiosyncratic and situational components of the individual. The literature indicates that lifestyle and severity of limb deficit have a substantial influence on prosthetic uptake, though the implications of other elements such as the age at which adaptation took place and the proficiency of training routines are still the subject of debate.

A comprehensive review by Scherer and Galvin (1996) of a number of studies on technology abandonment revealed that abandonment rates ranged from 8% to 75%, with an average of one-third of all assistive devices being left unused by users within the first three months of use. The degree to which people utilize current technologies varies greatly, with some individuals relying heavily on them with great satisfaction, while others only make use of them reluctantly and sparingly. There is an apparent linear relationship between the utilization of assistive technologies and the quality of life, and this interactive, dynamic connection between functional capacities, usage of technology, and quality of life alters over time.

A 1996 study conducted by Cushman and Scherer revealed that out of the 128 prescribed devices for participants with multiple disabilities, 86 were still being utilized three months later, while the remaining 42 had been rejected. Adapted toilet aids (55%), quad canes (43%), walkers (36%), and manual wheelchairs (36%) were the four devices most frequently abandoned, with the primary reason cited being that the device was no longer necessary. It has been suggested that the lack of individual involvement in the wheelchair procurement process may contribute to why wheelchairs are sometimes discarded, and researchers believe that further investigation into this process could help to improve outcomes for wheelchair users. Moreover, Mortenson et al. (2005) have indicated that wheelchair-related accidents are a major concern.

Phillips and Zhao (1993) conducted a national survey of 1732 devices, which revealed a 29% abandonment rate. Their research indicated that the highest rate of dropout occurred in the first

year, then again after five years. Additionally, four key factors were found to be strongly correlated with dropout: inadequate consideration of user feedback, difficulty in acquiring devices, subpar device performance, and a change in the user's needs or desires. Wheelchairs, bathtub chairs, canes, walkers, and long-handled reaches were the most commonly employed devices. Riemer-Reiss and Wacker (1999) found in their study that a large proportion of college students with various disabilities left behind their assistive devices and this abandonment rate was considered to be high. Mann et al. (1995) reported that the device rejection rate in their study was between 50%-54%.

In 2006, De Craen et al. evaluated the use of assistive devices among those aged 85 and over who were living independently in Dutch communities. Out of the 591 devices, only 74 (13%) were not being employed. To further understand the non-usage of assistive technology in the Netherlands, Dijcks et al. (2006) subsequently conducted a stratified survey among device users and found that 92% of the participants were using their devices.

Batavia and Hammer (1990) conducted a consensus-building process in which they interviewed twelve experienced technology users with sensory and mobility impairments in order to ascertain their purchase decisions. Four criteria were identified as the most important: effectiveness, affordability, operability, and reliability. Effectiveness was judged according to how well the device enhanced the user's functional capacity, affordability was based on the cost of purchase, maintenance, and repair, operability was evaluated in terms of ease of use, and reliability was measured according to the length of time the device worked without reduced performance. Ultimately, the study concluded that assistive devices that are effective, affordable, operable, and reliable are less likely to be abandoned.

Pape, Kim, and Weiner (2002) conducted an important evaluation of the elements that impact the adoption of assistive technologies, and concluded that for the effective incorporation of these tools into everyday life, potential users ought to consider their own interpretation of the technology, their expectations of it, the social expenses related to it, and their own conception of having a disability as a characteristic, not necessarily the defining one, of their own personal identity.

Vash (1983) identified a number of personal factors that have a bearing on the use and acceptance of devices, such as acceptance of disability, motivation, perceived daily activities, and the balance between effort and reward. His findings indicated that acceptance of disability and goal-orientation were associated with positive attitudes towards devices, while devices

which offer users the ability to achieve meaningful tasks were more likely to be adopted. Saladin (2004) cited Wright's assertion that those who are cognizant of the challenges posed by their disability but focus on overcoming them are more likely to utilize assistive devices.

Brooks and Hoyer (as cited in Philips and Zhao, 1993) found that those who claimed to have adjusted to their impairment were more reluctant to make use of personal care, cleaning, transportation, or mobility aids. They hypothesized that the need for frequent and sustained usage of these devices may engender a feeling of dependence for the individual who has adjusted well. This suggests that an individual's perception of autonomy might influence their acceptance and utilization of assistive technology.

In order to evaluate the views of mothers on the usage of hoists to tend to their children with severe physical disabilities, Shepherd, Stewart, and Murchland (2007) conducted a study. The results of the study indicated that some of the primary reasons for avoiding the use of hoists included the amount of time it required for the lifting process, the lack of contact with the child, the cost of the hoist, and the space it took up in the home.

A survey conducted by Garber and Gregorio in 1990 demonstrated that a substantial fraction (35%) of the assistive devices prescribed to people living with tetraplegia were being employed after two years. A retrospective audit of 100 service users conducted by Chamberlain, Evans, Neighbor and Hughes (2001) further revealed that the majority (83%) of the equipment and accommodations issued around 18 months to two years prior to the audit were still in use and were being used daily (69%). The results of the audit provided evidence that the supplied apparatus and amenities had become part of the individuals' daily life, and had been accurately recommended.

If a device that was carefully chosen ends up being discarded, it can be a cause of great concern and necessitate an investigation of the suitability of each step of the device's operation and all the people involved in the process. The literature in this area attests that the refusal of a device is the most serious and challenging problem in the field of assistive technology.

This chapter's literature review has thus far explored a variety of aspects of assistive technology and its services, thereby directing us to the discrepancies existing in this domain. Here, we endeavored to comprehend the problems associated with outcome studies concerning the devices, the effect of AT on subjective contentment, life satisfaction, and psychosocial effect, as well as the multiple elements that can have an effect on the psychosocial outcomes related

to the said device, especially when the device reaches its key stage, in which it will be decided whether to keep or get rid of it.

Assistive Technologies: A Sociological understanding

Assistive technologies can bridge the gap between the objectives of individuals with disabilities and the existing social infrastructure. These technologies can help to reduce the obstacles that impede full and equal participation. Technology is critical in fostering an all-inclusive atmosphere and building an accessible infrastructure, not only for persons with disabilities, but also for those without disabilities.

The contemporary world has witnessed the integration of technology into both local and global physical and virtual infrastructures. This has enabled persons with disabilities to use technology for a variety of purposes, ranging from internet banking to e-commerce and communication. Even though these technologies are available to all, it has been noted that when technology is referred to as an "assistive device" for disabled users, it tends to lead to a negative framing (Kushwaha, 2017). However, technology has also made a number of major contributions to the disability community, such as the introduction of Job Access with Speech (JAWS) and Non-Visual Display Access (NVDA) (for computer use), Kurzweil (for educational accessibility), MAGIC (for users with low vision), and the Braille Display Unit (for displaying texts in Braille form on computer screens).

The advent of tricycles, motorized vehicles, crutches and other mobility aids has enabled people with motor disabilities to move freely. In a similar vein, those with hearing impairments have benefited from hearing aids. The IT revolution has provided users with disabilities the opportunity to become integrated with the mainstream information cycle. Mobile phones and laptops, once seen as an impossible feat for blind people, are now achievable thanks to inventions such as 'eSpeak and Talks', 'Talk-Back' on Android phones and 'Voice-Over' on iPhones, which enable persons with disabilities to use mobile technologies without limitation. Moreover, thanks to the invention of JAWS, computer technology is now accessible to people with visual impairments. These technical advancements have enabled persons with disabilities to become everyday users of social media websites, professional websites and other online platforms.

Persons with orthopedic issues and motor disabilities are faced with the issue of limited mobility, yet technology has provided a solution. ATs have enabled them to live a life of less

dependency, greater autonomy, and enhanced freedom of movement. This is a result of the notion of 'independent living', which has been highly valued. Such technologies include crutches, wheelchairs, and motorized vehicles, which are now commonplace in a technology-driven world. This has enabled the disabled to experience a sense of 'independent life', and ATs have been instrumental in revolutionizing the lives of both disabled and non-disabled people alike (Kusuhwa, 2017). As such, these technologies can be seen as a source of hope for those with physical impairments, as they have given them the power to be independent in modern society.

The Convention on the Rights of Persons with Disabilities (CRPD) guarantees its beneficiaries the right to access assistive technology as a means to ensure that they can fully enjoy all human rights and fundamental freedoms. Nevertheless, in many countries around the world, access to assistive technology is still limited. According to the World Health Organization (WHO), only 5-15% of people with the need for assistive technology in low- and middle-income countries have access to it. Furthermore, less than 3% of the hearing aids required in these countries are accessible for those who need them. Estimates further suggest that only 0.5% of the population is able to acquire the orthotics and prosthetics they need, while only 1% of the population has access to wheelchairs, which is far from being sufficient (Borg, et al, 2012).

Consequently, the predicament is exacerbated by the reality that assistive technology is frequently given without consideration to the necessity for complementary services. These typically comprise of individual assessment, selection, modification, instruction, and monitoring to guarantee secure and effective usage. These services generally have a substantial outcome on the final cost. What's more, the availability of the environment is an essential requirement for utilizing certain varieties of assistive technology. Incompatibility with the environment may lead to the desertion of assistive technology (Shah, 2013).

The provision of substandard wheelchairs without the necessary clinical services, user training, and long-term local maintenance and repair services has been heavily criticized, as they can be potentially hazardous to the user. From a medical perspective, assistive technology is seen as a means of correcting any deficits an individual may have, while, viewed through the social model, it is perceived as a tool for reducing barriers in an environment that is disabling. The CRPD recognizes the importance of freedom of choice for individuals, which must be taken into consideration in this area, and emphasizes that assistive technology can be used both to

improve bodily structures and functions and to enhance activities and participation, ultimately removing any obstructions (Shah, 2013).

Regardless of when a person is diagnosed with a disability, they typically have a shared objective: to find and utilize devices that enable them to live as normal a life as possible and increase their productivity. The America's Technology-Related Assistance for Persons with Disabilities Act (1988) characterizes AT as a combination of both devices and services. An AT device is defined as any equipment, item, or product system, either purchased off the shelf, modified, or customized, that is used to improve, sustain, or augment the functional abilities of people with disabilities. This includes an extensive range of technology, from everyday life tools and prosthetic medical equipment to the most intricate computer communication systems. Furthermore, services are any facility that aids an individual with a disability in selecting, procuring, and using AT.

The World Health Organization (2004) defines AT as a general classification for any technology or system that assists an individual in completing activities which they would not otherwise be able to do, or that increases the ease and safety of performing certain tasks. Additionally, the Canadian Occupational Therapy Association (2003) describes AT in their position statement as "any device or product that helps enhance a person's functioning and engagement".

Scherer (1996) emphasizes the distinction between adaptive devices and rehabilitation technology, depicting the former as products created for general use but tailored to the needs of individuals with disabilities, while the latter is used to advance and facilitate their rehabilitation. Kraskowsky and Finlayson (2001) note that the terms 'adaptive equipment', 'adaptive device', 'assistive device', and 'assistive technology' are often employed interchangeably, although there are slight dissimilarities. Nevertheless, for the sake of clarity, they define it as "any object or tool that maximizes a person's autonomy in everyday tasks."

In 2006, Peterson and Murray proposed the term "rehabilitation technology," which they defined as the use of technologies, engineering practices, and scientific principles to assist persons with disabilities in educational, rehabilitative, occupational, transportation, and independent living endeavors, as well as recreation. Various entities and persons have articulated diverse perspectives on assistive technology, all of which are linked to a collective comprehension that AT holds great potential for those with functional impediments.

Since World War II, assistive technology has been part of the occupational therapy repertoire (Polgar, 2006). Occupational therapists, both in the public and private sectors, are prominently involved in providing equipment for people with disabilities (Mandelstam, 2001). These therapists are widely known for their role in prescribing AT and training individuals with disabilities to use these tools, as well as promoting and enabling the daily activities of people with disabilities (Finlayson, Guglielmello, and Liefer, 2001; Petterson, Appelros, and Ahlstrom, 2007; Waldron and Layton, 2008).

Samuelsson and Wressle (2008) emphasize that the efficacy of the prescription of assistive devices of various kinds is contingent on the expertise of the therapist, making the process a therapeutic one. A prescriber should be knowledgeable of the different products on the market, as well as being cognizant of each individual's physical, mental, and environmental budgetary constraints, needs, and preferences. Loebl (1999) proposed that the incorporation of technology into the rehabilitation and education of individuals with disabilities has expanded the scope of solutions to functional issues. Nevertheless, the difficulty of selecting the most suitable technology to satisfy people's demands has grown as well.

According to Nicholls et al., the intricacy of the communication not just originates from the special blend of physical, sensory, and intellectual capacities of an individual, but also the outlooks of the people (2006). Moreover, responses to cutting-edge innovations are intricate and vary greatly from person to person. The reactions that occur stem from a variety of needs, capabilities, inclinations, and prior experiences with technologies and the amount of exposure one has had to them.

An increasing number of studies demonstrate that assistive technology can give individuals with disabilities the necessary tools to complete everyday activities more efficiently. In 1998, a report by the National Institute for Disability and Rehabilitation Research (NIDRR) (as referenced in Jans and Scherer, 2006) highlighted how "technology makes a barrier-free world more achievable". This is essential for providing individuals with disabilities the opportunity to enjoy the same level of access as others. According to Ripat and Booth (2005), technology can bridge the gap between the abilities of a person with a disability and their desired goals.

The utilization of technological tools has been shown to have a positive effect on those living with disabilities; it can alleviate residual affliction, defer deterioration of function, reduce the necessity of care, and lower healthcare expenses (Jutai, et al., 2007). Moreover, Peterson and Murray (2006) contended that technology has offered more personal and professional prospects

for persons with disabilities. It serves an essential purpose in the lives of people with disabilities, as it can tackle issues concerning functional recovery and advantage. Furthermore, Gallagher (2003) proposed that technology can empower individuals with disabilities to take part in society more actively and to enhance the quality of life.

The effects of assistive technology can be observed in the lives of users and their environments, such as a decreased reliance on others and a greater access to social resources (Fuhrer, 2007; Lenker, Scherer, Fuhrer, Jutai and DeRuyter, 2005). To measure the impact of these changes, studies must use valid and reliable metrics that can be understood and applied by stakeholders. The impact of these changes may be minor for some, yet deeply meaningful for others.

Despite making considerable advancements in the professional and political fields, it has been observed that outcome measures are not regularly implemented in everyday practices. People seeking help have a wide range of outcomes that are based on the same fundamental principle of being able to take part in daily activities with maximum autonomy. This typically includes the freedom to go out, mingle and engage in meaningful activities. Nonetheless, the results are contingent on various factors, such as independence, safety, simplicity of tasks, advancement of options and control, user gratification, social care, time following the provision of apparatuses, functional state of the person, particular health conditions, the approach of application, and levels. These parameters are particularly pertinent and have been employed to facilitate the user's benefit, contentment, and general satisfaction. Incorporating them into the assessment of services can produce the desirable outcome (Heaton and Bamford, 2001).

Inoue et al. (2003) argued that the complexity of the user's characteristics, their daily life, the involvement of various stakeholders, the social system, and other settings all lead to difficulties in the development of assistive technology. Kraskowsky and Finlayson (2001) added that the inappropriate prescription and distribution of adaptive equipment result in the squandering of both public and private funds and time.

The provision of AT services in different regions can differ drastically, with some systems being efficient and integrated, where others are seen to be lengthy, complex, and disjointed (Ripat and Booth, 2005). According to the NCD's report (cited in Hunt et al., 2004), a substantial number of people with disabilities remain deprived of existing public and private programs.

Studies have demonstrated that individuals may reject or discontinue the use of what seem to be well-crafted and functional devices. If these prescribed technologies are not employed, the repercussions can be severe. Therefore, in order to increase device adoption, retention and avoid rejection, designers and vendors should gain a more thorough comprehension of the psychosocial components that could influence the adoption, continuation, and discontinuation of the device. As Gallagher (2003) notes, the majority of time spent in the office is dedicated to resolving the mechanical issues of the prosthesis, leaving few chances to tackle the psychosocial issues that may be experienced by the user.

Despite the technological availability of assistive technology, studies have found that it is underutilized by those with physical disabilities, a concerning issue that needs to be addressed. Peterson and Murray (2006) note that, on average, just one-third of the devices supplied to customers are actually employed, representing an unsatisfactorily high rate of non-utilization for both the consumers of these services and the providers who fund them.

Non-medical psychosocial factors have been identified as a main cause for why a number of people do not utilize or cease to use their assistive technology (AT) devices. According to Rogers' diffusion theory (cited in Riemer-Reiss and Wacker, 2000), discontinuity is an act of discarding an innovation that had been previously accepted. There are two kinds of discontinuations: substitution (the rejection of an innovation for an improved one) and disenchantment (the dismissal of an innovation due to dissatisfaction). Harris (2007) pointed out that participation in society can be a challenge for people who use mobility devices on wheels. Even with the availability of more accessible buildings, those who use mobility devices still take fewer trips out of their homes and partake in fewer activities compared to those without disabilities. Wheelchairs are highly visible markers of disability and, in fact, have become symbols of this, both literally and culturally. Statistics show that more than 90% of wheelchair users experience some kind of activity limitation and only 14.7% are able to complete all mobility tasks associated with daily life.

In his 2002 paper, Scherer points out the difficulties encountered by consumers in obtaining the ATs needed for leading a healthier, more autonomous, and more fulfilling life. He stresses the importance of consumer education, consumer participation in the evaluation and decision-making process of ATs, and the need to ascertain the preferences and priorities of the relevant individuals.

The research of Fuhrer, Jutai, Scherer, and De Ruyter (2003) suggest that there is a need for research focused on both quantitative and qualitative approaches to functional outcomes due to growing demands for accountability in medicine and related health fields. Heaton and Bamford (2001) affirm that evaluation of new products, technologies, and service delivery is necessary, including measuring the results for service users. Yet, in the wake of recent events, there is a greater need for professional responsibility. This highlights a disparity between the points of view used to study medical devices, and the approaches proposed by Sprigle (2007) to evaluate functional devices.

Fuhrer et al. (2003) noted that, despite the significant strides made in the development of assistive technology, research to evaluate the effectiveness of these innovations has not kept pace. This discrepancy can be attributed to a variety of causes, such as the notion that the advantages of AT are self-evident when, in fact, they may need to be articulated explicitly. Additionally, those responsible for building and designing AT tend to focus more on demonstrating technical proficiency and mechanical characteristics than on evaluating user performance. Furthermore, the lack of attention to psychosocial aspects, the lack of adoption theories, and the dearth of regulations requiring the collection of data on outcomes have all contributed to this deficit (Shah, 2013).

Assistive Technologies in the Indian Context

In 2011, according to the World Bank, India, the second-most populous country in the world, was home to approximately 80 million individuals with disabilities. Most of these individuals were located in rural areas, where the lack of development has caused multiple disabling barriers. Zipfel, Cooper, Pearlman, Copper, and McCartney (2007) noted that the number of people with mobility disabilities who need wheelchairs in developing countries is estimated to be between 20 and 100 million. Moreover, the authors estimated that 95% of this population does not have access to the wheelchairs they require.

The rehabilitation of disabled individuals in India has been significantly influenced by culture and tradition (Chaudhary, 2012). Unlike in the West, the provision of assistive devices and technologies is not typically incorporated into the health system, but rather is managed by non-governmental organizations and other groups. Unfortunately, this lack of central coordination means that the needs of persons with disabilities, as well as their living conditions and environments, are not always taken into account when producing and distributing assistive devices and technologies (Singal, 2006).

In India, the most commonly utilized forms of assistive technology are those provided through donations and workshops by NGOs. These organizations, typically tied to religious beliefs or institutions, are driven by benevolent intentions, rather than any distinct socio-political ambitions. Unfortunately, they are often reliant on foreign funding to cover all disabled individuals, regardless of region, type, gender, or age, without any input from disabled citizens themselves. This is a pervasive and multifaceted issue, the result of a combination of high disability rates, subpar healthcare access and quality, insufficiently designed products, manufacturing deficiencies, a lack of product standards and testing, inadequate delivery systems and services, and sociocultural barriers to the rehabilitation and acceptance of persons with disabilities.

According to Pearlman, Cooper, Zipfel, Cooper, and McCartney (2006), the charitable distribution model is widely regarded as an effective approach to quickly supply a great number of wheelchairs to an area of need. Nevertheless, detractors argue that this method of allocation is not sustainable and the wheels may not be suited for the particular region. Mukherjee and Samanta (2005) further highlighted that most often different social welfare groups offer their assistance to individuals with physical handicaps, and, typically, the wheelchair is allocated to those who cannot walk on their own.

Most wheelchairs are distributed by NGOs and voluntary organisations in a random manner, these being cheap, locally-made, rigid-type, conventional rim-driven manual wheelchairs. This has led to a strong rejection of the distributed wheelchairs by the disabled population due to their lack of fitness for regular use. According to organisations fighting for the rights of persons with disabilities, the cost of supporting those with disabilities in India is considerable and would require considerable financial resources. Awareness of AT is limited in the Indian subcontinent, and there are both financial and social difficulties in implementing them. Both persons with disabilities, health professionals and policymakers are largely unaware of the possibilities and current developments in AT-related issues in India (Chaturvedi and Ramesh, 2005).

The Indian policy framework pertaining to disability is codified in three key pieces of legislation: the RCI Act (1992), the PWD Act (1995), and the Trust Act National (1999). These laws necessitate a basic level of access to assistive technology (Shah, 2013). Moreover, the Mission Mode Science and Technology Project (1986) enables research and the development of appropriate, innovative technological devices. Additionally, the ADIP scheme provides

disabled children with the opportunity to purchase and install modern, standard, durable, and scientifically produced aids and appliances, which can improve their physical, social, and psychological well-being.

Over the past decade, there have been numerous studies conducted concerning the use of assistive technology, yet the body of knowledge regarding the individual interpretation of such devices in everyday life is still relatively small but steadily increasing. Scherer and Cushman (2002) point out that it may be attractive to promote technologies that would help those with disabilities become more independent in their activities, but it is crucial to take into consideration the quality of life, subjective well-being, expectations, and environmental support for the use of technology as well as social engagement based on their functional abilities. Wielandt, Mckenna, Tooth and Strong (2006) conducted a study which revealed that clients wanted services that acknowledged their opinions, beliefs, and perspectives; services that would provide them with an opportunity for choice, autonomy, and reintegration into the community.

Measuring user satisfaction (Demers et al., 2002; Kittel, Di Marco, and Stewart, 2002) and understanding the perspectives of consumers (Scherer, 2002) are both essential to the effective management of AT. Data gathered from surveys, such as those related to satisfaction, can help clinicians, researchers, managers, and buyers to make improvements, while also cultivating a positive attitude among users, thus reducing churn rates and curtailing replacement costs. Furthermore, satisfaction is closely linked to quality of life. Therefore, it is essential that research should concentrate on the difficulties that users may face when using technology, the problems that could overwhelm them, the need for significant adaptation and change, and the individual skills that have inherent value (Yonezaki et al., 2003). By gaining a sociological insight into the implications of technology, not only may the well-being of the user be enhanced, but the most efficient use of the technology may be ensured.

In spite of the fact that Kirby and Cooper (2007), Mukherjee and Samanta (2005), and Zipfel, et al. (2007) have provided evidence of the physical aspects of the devices in their studies, it has been largely neglected to consider the non-physical or psychosocial needs in both research and practice. It is also of great concern that a lack of sensitivity and consideration for the users' point of view is pervasive in the addressing of problems.

Current reports demonstrate that most research on users' viewpoint is based on Western society; however, the pertinence and practicality of the findings from these studies are somewhat

limited when applied to the Indian social setting. Indian society is dissimilar in terms of socio-economics, socio-culture, and socio-politics in comparison to Western civilization.

Conclusion

In India, there is a dearth of research that looks at the sociological and psychosocial aspects of an individual with motor disability adapting to assistive technologies. The service and support systems in this area are mostly influenced by medical and technical perspectives, failing to take into account user feedback. This negligence of user requirements is likely a product of the traditional understanding of disability, which tends to be seen from a charitable standpoint. Therefore, the need to look into this particular field and explore the lack of research in this relevant area is essential.

The next chapter will move from historical documentation to present the main findings of the empirical research. Through interviews with persons with disabilities, it should be possible to ascertain some reasons that assistive devices are used or abandoned, and the factors that affect the success and failure of said devices. It should be remembered that the point is not to find arguments against assistive technologies, but rather to understand what causes those arguments to emerge organically so that we are better positioned to propose changes to existing structures that may lessen the issues that prevent both the spread and the initial adoption of assistive technologies.

CHAPTER 4

Negotiating Disability: The Field View

The present chapter details the experiences of the respondents who have locomotor disabilities and their family members vis-à-vis disability, medical interventions, institutional exigencies related to accessing assistive technologies. It presents the empirical data collected from the field from the respondents on their perceptions on negotiating disability. The previous two chapters, i.e., chapter two and three, dealt with the academic discourse on disability and assistive technologies and their historical antecedents, chapters four and five will focus on the empirical findings of the study.

In this chapter empirical data on the social construction of disability and assistive technology is presented. It explicates the role of significant others, including family members, generalized others, medical professionals, etc. in the construction of identity vis-à-vis use of assistive technology among persons with locomotor disabilities. It attempts to bring out the dynamics of structural aspects of disability construction influencing adoption, coping and decision-making strategies.

The perceptions of persons with disabilities on social relations within the family, friends and peers, and their feelings about social institutions like family, education, marriage, etc. helped understanding how identity and disability are socially constructed, culturally conditioned and personally negotiated. The experiences and the roles that persons with disability take on as they construct their 'identity' within the family and other social institutions are explored in this chapter. Family members' (parental, as well as spousal) perspectives and experiences of having a child with a disability, and support for the disabled child in negotiating social interactions within and outside the family, and the coping strategies adopted have been captured through personal informal interaction with parents of persons with disabilities.

Interviews carried out with family members (parents or spouses), siblings, and persons with locomotor disabilities provided the basis for understanding the problems that the latter face within the family and outside the immediate family and how the 'significant others' play an important role in the construction of disabled identities during their formative years. This chapter further attempts to understand the nature of accessibility to assistive technology for

persons with locomotor disability and their experiences within the social institutions of family, marriage, education, and health.

Social institutions play a major role in shaping the experiences of PWDs in general. They have positive experiences within the family and the support from peers helps them to play their roles effectively as opposed to the negativity usually associated with their disability outside the family realm. The construction of identity by PWDs is explored through their feelings about their bodies. This is done through in-depth interviews with them. It focuses on the critical aspects of the self – physical appearance, likes/dislikes, and achievements, the participation of PWDs in social institutions like family, marriage and education.

Data were collected from sixty respondents who have locomotor disability availing prosthetics or orthotics from Institute of Medical Sciences-Artificial Limb Manufacturing Unit (abbreviated as IMS-ALMU) and Orthofit, a private for-profit organization, and those who avail medical services at IMS.

Institute of Medical Sciences (name changed) is a state funded organization located in Hyderabad specializing in orthopedic treatment. The Institute of Medical Sciences (IMS) was established in 1961. The objective of IMS is to serve as a "center of excellence" for medical science, with a special emphasis on orthopaedics. IMS is now respected as an affordable and trustworthy healthcare provider and institution by people from all social classes. The Department of Orthopaedics remains the oldest department in the hospital, having existed since 1964. This department has become one of the most trusted specialty care in orthopaedics, backed by a state-of-the-art infrastructure. The department now proudly serves patients from all over India.

The Artificial Limb Manufacturing Corporation (ALMC) aims to provide support to those persons with orthopedic disabilities who want to go for prosthetics. Under the scheme 'Assistance to Disabled Persons in Purchase of Fitting Aids and Appliances (ADIP)', assistive devices are distributed at no cost for the needy whose annual income is less than one lakh rupees. -Artificial Limb Manufacturing Unit (IMS-ALMU). ALMC established artificial limb manufacturing units in reputed orthopedic hospitals in all major cities in India and one such unit was set up in IMS. For data collection purpose the researcher established contacts within the orthopaedics department and visited IMS hospital several times. The researcher was eventually introduced to patients by the doctors at IMS-ALMU.

Orthofit is a Germany based company, established in 1919, where it was founded by the prosthetist Otto Bock. The company has grown into a worldwide organization, serving more than 46 locations in over 100 countries. Its headquarters in Duderstadt, Germany, still keeps Bock's vision alive today and is just as dedicated to restoring mobility as ever. Bock transformed the field of prosthetics in the early 20th century, applying modern manufacturing techniques to create interchangeable and customizable components that were unique to each patient. His pioneering efforts allowed prosthetists around the world to meet the demand during and following World War I, giving veterans the power to stay active in their daily lives.

Orthofit and IMS-ALMU are providing prosthetics and orthotics. However, IMS-ALMU provides the assistive technology devices (ATDs) free of cost while Orthofit charges for the ATDs. Those who can afford avail the ATDs from Orthofit. The Head of the department at IMS-ALMU reports that around five out of every 25 patients who approach IMS-ALMU can afford higher technologies provided by private units like Orthofit. It was observed in the study that the Orthofit maintains close contact with the IMS-ALMU for the references of prospective users of Prosthetics and orthotics. Those orthopedically challenged patients belonging to upper class and upper middle class are referred to Orthofit by the doctors of IMS-ALMU.

In all, sixty respondents from both the institutions were identified for the study and data were collected from them. Family members (parents and spouses) of these respondents were also approached to gain greater insights to understand the structural considerations in identity formation. Interviews with the doctors treating the respondents also helped in understanding the perspective with which the medical science approaches disability, particularly, locomotor disability. The sites of field work are state run and private assistive technology device providing units located in Hyderabad.

Persons with disabilities play various roles in the process of social interaction with others. Their perception of self and the construction of identity is embedded in the roles that persons with locomotor disabilities play as parents, employees, wards, students, and peers. A detailed account of the everyday experiences of the orthopedically challenged within and outside family, with assistive technologies, medical fraternity, device providers, etc. is provided in the form of fifteen case studies.

Profile of the Respondents

Out of sixty respondents from whom data were collected fifty-two are unmarried and eight are married. Gender composition of the respondents is that thirty-two respondents are men (including married men) and twenty-eight are women (including married women). Data on educational background suggest that the thirty-one respondents have studied in regular schools and colleges and twenty-nine are drop-outs due to constraints like inaccessible school and college buildings, inaccessible public transport, financial constraints, etc. Age of the respondents range from one year to forty years. Five respondents are in the age group of 1-10 years, out of which 3 are boys and 2 are girls, eighteen are in the age group of 10-20 years, out of which 10 are boys and 8 are girls, twenty-nine are in the age group of 20-30 years and the remaining eight are in the age group of 30-40 years. Majority of the respondents belong to middle income category while thirteen belong to upper income category.

Table 4.1: Profile of the Respondents – Gender, Age and Education

Category	**Category**	**Number of respondents**
Gender	Men (including unmarried respondents)	32
	Women (including unmarried respondents)	28
Educational status	Regular School/ college	31
	Dropouts	29
Age Group (in years)	1-10	05
	10-20	18
	20-30	29
	30-40	08
Assistive Technology Users		**40**
	Men	27
	Women	13
Non- Users		**20**
	Men	07
	Women	13
Extent of loss	40%- 80% (moderate impairment)	47
	> 80% (profound impairment)	13

As regards the extent of disability, forty-seven respondents have moderate disability (40-80 percent impairment) and thirteen respondents have a profound impairment (above 80 percent impairment). Out of sixty respondents forty use assistive technologies (twenty-seven men and

thirteen women) and the remaining twenty are non-users (seven men and thirteen women). The non-users belong to both moderate and profound levels of impairment.

Out of sixty respondents from whom data were collected fifty-two are children (un married living with parents and siblings) while eight are adults (i.e., married). Out of these fifty -two respondents sixteen respondents reported the family size as five and above while the rest forty-four respondents have less than five members.

Table 4.2: Respondent's Family Background

Family composition		No. of respondents (52)
No. of family members	3-5	45
	5 and above	7
No. of children with disability	1 Child	48
	2 Children	4

* Out of 60 respondents 52 are children (unmarried living with parents) and the remaining eight are adults.

Out of fifty-two unmarried respondents forty-eight have reported them to be the only child to their parents (i.e., the respondent) suffering from locomotor disability in their family, and four had another sibling (i.e., respondent and his/her sibling) suffering from disability in their family.

The socio-economic background of parents is important to understand the respondents' disposition towards disability. This was attempted by using data collected from respondents on their parental background. This data was collected from both adult as well as unmarried respondents of the study.

Table 4.3: Socio-Economic Profile of the Parents of the Respondents

Status	Category	No. of respondents (N=52)	
		Father	Mother
Education	No formal education	17	26
	Secondary	15	14
	Higher Secondary	11	9
	Graduation	9	3
Occupation	Homemaker	-	30
	Homemaker and involved in petty home based work	-	14
	Cultivators	11	1
	Self – employed	17	1

	Wage – earners	12	2
	Govt/ Private Employee	12	4
Annual Family Income	Combined income of both parents		
	Low (< Rs. 2,00,000)	19	
	Middle (Rs. 2,00,001 - 6,00,000)	20	
	High (>Rs. 6,00,001)	13	

Data collected from fifty- two unmarried respondents on levels of education, occupation, and income of the parents of the respondents is presented in Table 4.3. On father's education, seventeen are non–literate, fifteen have secondary education, eleven have completed higher secondary school or plus two and nine have completed graduation. Five respondents' fathers have professional qualifications like B.Ed., M.Ed., B.Tech., etc. The educational status of the mothers is relatively low as twenty-six mothers are non-literate, fourteen have completed secondary education, nine have completed higher secondary, and three have completed graduation.

As regards employment, seventeen respondents reported that their fathers are self-employed engaging in small businesses, twelve are employed in government or private sector, twelve are wage earners and the remaining eleven are cultivators. Among the mothers of the respondents a majority (i.e., thirty) are homemakers. Fourteen are engaged in income generating household level works like beedi rolling, agarbatti and papad making and tailoring. One is engaged in cultivation and another one runs a small grocery store. Mothers of two respondents work as wage earners in the day time and in the evening, they work as domestic helpers. Four are employed in government or private sector.

Annual family income was recorded in terms of both the parents' income. Nineteen respondents' annual family income is less than two lakh rupees per annum. Twenty respondents reported their annual family income as less than six lakhs rupees while thirteen respondents as more than six lakhs. Among the thirteen respondents whose family annual income is above six lakhs it was observed that mothers of three respondents earn about a lakh rupees per month.

Socioeconomic Profile of Adult Respondents

Data was collected from eight adult respondents. Among eight respondents three were men and five were women. Out of three men respondents one respondent has two children, one has one child and one has no children. Among the five women adult respondents four have two children and one has no children. Importantly, four women who gave birth to two children each, reported

that their children were born without deformities. This proves the stereotype that women with deformities most likely to give birth to children with deformities wrong.

Table 4.4: Socio-Economic Profile of Adult Respondents

Status	Category	No. of respondents	
		Men	Women
Education	No formal education	1	2
	Secondary	1	-
	Higher Secondary	-	2
	Graduation	1	1
Occupation	Homemaker and involved in petty home-based work	-	3
	Wage – earners	1	-
	Govt/ Private Employee	2	2
Annual Family Income	Low (< Rs. 2,00,000)	3	5
Children	One child	1	-
	Two children	1	4
	No children	1	1
Rural	Rural	2	4
	Urban	1	1

As regards the educational levels of the adult respondents, out of three men, one has passed degree, one has intermediate qualification and one has stopped with school education. Among five women adult respondents one has passed degree, two have passed intermediate and the rest two have no formal education. On employment, out of eight adult respondents, two men are employed in private sector while one man has no income source and he reportedly eking out his livelihood by begging. Out of five married women respondents two are employed in private sector and three are engaged in income generating activities like beedi rolling, agarbatti making, etc. from home. Out of eight married respondents six (two men and four women) reported their income to be below two lakhs per year while two (one man and one woman) have annual family between two and six lakhs.

Perceptions on Disability by Self, Family Members and Medical Professionals

Data were also collected from the family members i.e., parents, siblings; and spouses, daughters, sons (married respondents) of the respondents. Through informal interviews with the parents and family members their experiences of disability in the family as a result of an

orthopedically challenged family member were elicited. There are around fifty conversations recorded with the consent of the parents of the respondents. Observations from their conversations are interspersed with the primary respondent's data in this chapter. The bearing of an orthopedically challenged family member on the social, financial position of the family were ascertained in the interviews. The expenditure incurred on the care and education of a family member with disabilities, and for the support services were ascertained. Conversations with doctors is presented contextually along with the presentation of data from the respondents.

Understanding family members' perspective is considered critical for the study because close, inner, critical information about the experiences of the family members in the interaction with the disabled family member provides insights into interpretivist account of everyday life of persons with disabilities. Researcher's interaction with family members revolved around issues of social importance like family relations- within and outside, education, career, marriage and employment of their disabled son or daughter. An attempt has also been made in this section to understand the relation between socio-economic status of the parents and the support given to the disabled child.

Disability can be congenital (occurs at birth) or acquired in early childhood, between ten months to two years of age, or can occur at later phases of life as a result of vascular disease, trauma, malignancy, or an accident. In the case of congenital impairment identification of impairment of the child is known to parents first, and more precisely the mother. A doctor, general physician, with whom the researcher interacted during the study, observes, *mother is the first and the best doctor to recognize the child's problem irrespective of her educational background* (Dr. Anitha, MD, General Physician).

Parents can make sense of the abnormality through symptoms which vary according to the type of impairment. Parents can notice impairment like; deformities in arms and legs, face; delay in walking, speaking; problems in hearing and cognition; problems of certain functionalities in specific body parts; are indicative of an existing or impending impairment in the child. Parents become concerned about the problem and eventually seek medical advice. A doctor observes that, *some impairments are invisible but could be noticed within ten months to two years after birth. We cannot diagnose until they attain the age to walk, as their bones are soft for a certain period. Children cannot withstand the weight on their legs until ten months to one year, depending upon the child's growth* (Dr. Ashwin, Physiotherapist). This suggests that parents are the first persons to notice the onset of impairment and doctors only confirm the impairment.

Ailments like fever, chronic illness, polio in the early childhood, consanguineous marriage among parents or an accident result in the impairment. A mother of a respondent reports *I had a normal delivery, but then my daughter was born with twisted limbs. Her disability might have been caused by our consanguineous marriage*. Most of the respondents (thirty-three out of sixty) reported that their impairment was the result of consanguineous marriage among their parents. Either their parents are married to their father's sister's son/daughter called *Bava/maradalu* (cross cousins) or to mother's brother called *mamayya* (maternal uncle). This kind of marriage used to be quite common in the rural areas of Andhra Pradesh and Telangana. However, it is being discontinued because of the growing awareness among people.

Data from the respondents suggest that almost all the parents, after recognizing the problems of growth and functions in their children, immediately sought medical help. Every parent, irrespective of class, educational background, or status tried their best to improve their child's functionalities through medical care, either by approaching a good doctor at a big hospital or by approaching their local doctors. However, variation in education, occupation, region, and economic status of the parents did have a visible impact on the way they addressed the child's disability. For instance, those parents of the respondents who are well educated and economically well off were interested in learning more about the underlying meaning of disability, its symptoms, treatment, etc. Educated and employed parents could address the impairment better, both medically and emotionally.

Even doctors tried to explain the meaning of disability to some of the educated parents. One of the doctor respondents says that *doctors are considered to be Gods but, according to me, they cannot even consider to be demigods. Because we just don't have the powers to change their deformed bodies. The so called 'body' that is given by God cannot be changed by science or doctors. We are human beings like any other. At the maximum, we can try to improve their functionalities* [Dr. Raju Ayengar, M.S (Ortho Surgeon)].

The educational levels of the parents appear to be an important factor in the lives of the children with impairment. In the words of a doctor *when an educated parent or patient comes to us, we feel a little relieved when compared to a non-educated parent or patient. We try to explain to them about their condition and ask them to understand their condition first. We tell them that no surgery will help in changing their disabled identity. The only hope we can give to the patients is - there would be certainly an improvement in functionalities. Although, at times it is*

difficult to convince educated parents as well but compared to non-educated parents or patients they understand better' [Dr. Nitish Bhan, M.S (Ortho Surgeon)].

Some of the educated parents reported that they went to counselors like professors and doctors and read the available literature regarding coping strategies on the internet and browsed the motivational videos of successful disabled people. A doctor said, *we (doctors) give our patients hope that we are there to help them in doing things in everyday life independently to some extent. We can't assure our patients that, "oh! If you don't have a limb, after surgery you will get the limb." We don't try to give them false hope.* [Dr. Yakub, M.S (Ortho Surgeon)]

Parents of the respondents observed that gaining an understanding of their child's chronic condition was important to help them address the disability of their child in a holistic (medically, psychologically, socially) way. *I do remember when Tarun was diagnosed with a congenital deformity of eighty percent of locomotor disability by the doctors, we simply could not leave it at that. We spoke to some of our known doctors in our friend's circle. We even brought a few books on how to cope with a child with a disability from the doctor who actually diagnosed his problem. Even the physiotherapist wanted him to do small things on his own. We have decided that we will bring him up very independently like any other so-called non-disabled child. We felt that there is a need to understand impairment.* [Tarun's Mother]

Some parents sought suggestions from doctors for easing their situation. *When Akhila was diagnosed with multiple abnormalities, I remember the doctor who was supposed to operate on Akhila had shown us very inspiring videos of disabled people. He was mentally tuning Akhila to develop confidence in her and making her face the world. Then we started searching other sources for Akhila to improve her confidence levels. As a headmistress, I discussed with my colleagues and spoke to professors and doctors to understand the problem in depth.* [Akhila's Mother]

In a few cases, the impairment was not congenital but was acquired as a result of an accident. For one respondent, orthopedic impairment occurred in her early teens, and it was a difficult situation for herself as well as her parents and siblings. They were unable to digest the bitter reality of her not having limbs even after many years after the accident. *At the age of eighteen years, she met with one of the greatest tragedies in her life. She met with a terrible accident when she was returning home after giving her plus two exams. In that accident, she lost her leg. She was otherwise perfectly normal at birth* [Pravallika's brother].

Recalling his accident Pranay, who lost limbs in an accident says, *I wanted to give a surprise to my grandparents but in turn, God has given me a big surprise which I didn't even dream about it – A person with both limbs turned into a person without a limb* [Pranay, 28 years.].

Any references to *karma* or previous birth's deeds or fate are outrightly rejected by disability scholars (Ghai,2001; Anand cited in Addlakha, 2013; Mehrothra, 2013;). However, it was observed in the study that few respondents and their parents refer to fate and karma as a way to cope with the emotional and social stress. Padma, a respondent, says *God has written a dark phase of life in my destiny*. Mother of another respondent takes solace in the theory of sins of previous birth saying "*Na bidda ilaa puttindi ante poorva janma paapam"* which means that my daughter's impairment was the result of my past birth misdeeds (Anusha's Mother).

Some parents of the respondents opined that, doctors at primary healthcare centers and local doctors [Registered Medical Practitioners (RMPs)] don't have a clear view of what a child is going through. Lack of awareness on the part of the parents and, in some cases, financial constraints led to negligence. It was reported by a few mothers, who come from poor families in rural areas, that doctors reportedly gave the reason for the impairment of the child as lack of nutrients during pregnancy. One of the respondents observes that: *in my house, first the men in the house like my father–in–law, my husband, my husband's brother will eat, then after that the women of the house are supposed to eat the remaining food. When I was pregnant, most of the time I remember eating rice mixed with water* (Aditya's Mother).

Families with low income could not afford adequate nutritious food for pre-natal and post-natal care of the mother. This might also have resulted in the disability of the child. It is a common practice in many families in rural and urban areas that the pregnant daughter is taken to the natal family by her parents during pregnancy. This custom was followed to provide sufficient food and rest to the pregnant women. Around the end of the seventh month of pregnancy, in general, the pregnant daughters are under the care of their own mothers. This ensures sufficient rest and time to prepare for a safe delivery of a healthy baby. Even now delivery is considered to be a responsibility of the pregnant woman's mother in many parts of the country.

Disability and its Impact on Family Life

Parents of the unmarried respondents reported that daily chores including toileting, nursing, brushing, bathing, washing clothes, combing hair, feeding, lifting, and the extra care needed during the pre- and post-surgery treatment of the child, which may become the lifetime norm

for some cases, were physically very painful and stressful. Especially, mother is reported to go through a very stressful phase. As children grew older, they continued to be dependent on their parents and they required continuous attention and supervision. This became increasingly difficult when the disabled child gained weight due to being bedridden, limited physical activity, sedentary lifestyle largely confining to home. Apparently, it is an even more painful situation to handle when parents also grew older.

Disability not only affected the person suffering from impairment but also caused physical and emotional stress among parents. The physical strain is because of the medical attention, including lifting and moving, required for the child since birth. Some parents said they also developed ailments like blood pressure, sciatica, etc. due to depression and continuous crying. *I was in despair during the initial days when I had decided to be with my child and to leave my husband. I continuously cried for a few months, I had no one to share with what kind of phase I went through. Slowly I made my mind stronger* [Akhila's Mother].

Treatment for ailment of the child for a longer duration caused physical strain on the parents leading to their ill health. *My wife developed the problem of sciatica (severe backache) when she was taking care of my daughter who underwent eight surgeries with sixteen fractures for about four years. She used to lift her for toileting and bathing. Now she can't do some activities because she was physically strained for so long* [Nisha Gopika's father about her mother].

It was noted in the conversations with mothers of girl respondents that care work is harder for mothers, especially if it is a girl because they need special help during their menstrual cycle. *I used to get tired a bit during her menstrual cycle, apart from washing her undergarments when they got soiled during her periods, I've to clean the floor due to stains that spread on the floor. I cannot go to duty on those days as I cannot leave her alone* [Bhargavi's Mother].

Also, the adult respondents sounded the issue of aging having an impact on their functions. *It is very difficult! You have to depend on many people. I'm dependent on both my daughters to a great extent that for every fifteen days both my daughters exchange the shifts to look after me because I can't just go to the kitchen and set the table. After everything is prepared, my husband and my son lift me and take me to the table. I'm an overweight person… it is a burden on my husband and son to lift me all the time* [Saheena Kathoon, 40 years old].

A women respondent with disability reported that she had to compromise on her treatment and corrective surgeries fearing causing burden on her family members. *I stopped my treatment*

after one surgery. The doctor suggested to me that I need to go for two more surgeries; I stopped with one because both my mother and father passed away during my early childhood and my elder sister and brother–in–law took decent care of me. For my first surgery, I was hospitalized for six months when my elder sister used to take extra care of me by doing my daily chores, managing my everyday tasks like feeding, toileting, washing clothes; it was even more difficult to wash clothes during my menstrual cycle for about a year. I don't want to give my sister this extra burden, for my well-being, by undergoing another two surgeries. Though my sister did her responsibilities very religiously, I was feeling guilty about it; I felt that she is my mother, not my sister [Harini, 30 years old].

Parents and siblings opined that besides coping with the mental stress of having a child with a disability or having a sister or brother with a disability, it's also difficult to devote enough time in taking care of them. While parents were supposed to devote extra time to their disabled children, the siblings in the family reportedly felt that they were neglected at the cost of their disabled sibling. It was reported by parents that the siblings felt their mother's love and care was decreasing for them. *When I used to feed my daughter (who is disabled) every day before I used to go to my office my other three children used to ask, "why are you showing extra love for her. Anyways she won't be able to take care of you when you become older. How can you expect her to take care of you when she cannot take care of herself? We are the people who are going to take care of you when you become older. Try to take your free time for us rather than paying attention to her*" [Bhargavi's Mother].

The interactions with respondents' parents reveal newer dimensions on the emerging nature of family, particularly in the case of families with disabled children. In traditional families, they used to give a lot of support when a child is suffering from illness or physical disability but now, in modern families, they are thrown out of the house along with the mothers. *My in-laws asked me and my daughter to get out of the house since I gave birth to a girl child with twisted legs. They used to ask me, "Kaalu leni pilla ni emi choostamu?" (How we can take care of a girl who doesn't have legs?) and accused me of giving birth to "vankara kaalu pilla" - girl with twisted leg* [Mother of Jyothi, 1½ year girl].

The reaction of in-laws to the news of the delivery of a disabled child by their daughter-in-law reported to be aggressively negative. Narrating her ordeal, Akhila's mother says, *when she gave birth to two disabled daughters, her in-law's reaction was most inhuman.* She says, *Akhila was also born with a congenital disability, as a result, my in-laws, including my husband, gave*

me two options: one was, they asked me to leave the child at the hospital and asked me to come with them, or else they asked me to stay back with the child forever. I'm a mother; I've chosen the second option, which was the toughest decision [Akhila's Mother].

In some cases, the family members, particularly the husband or father and mother-in-law, allowed the mother with the child born with disability to come home only when she brought more money from her parents. *I have promised my husband that I will not ask anything for Bhargavi (who was born with impairment). I just want to keep my child as long as I live. Then my husband accepted both of us into the house and he demanded an extra 100 sq. yards of land in Janagam (a small town near Hyderabad) from my parents as a token of gift to keep the disabled child with us* [Bhargavi's Mother].

Parents also reported that their children had trouble accepting the lives they'd been born into. Children felt pain, emotionally and physically, as years passed. The parents felt they were depressed and distressed when there were instances of name-calling like *Kunti*, (hoping/limping) *vankara* (twisted), *Kaalu leni vallu (absence of legs), nadavalenivallu* (unable to walk) or other unkind remarks by their peers and kin group members. Due to societal influence, some respondents reported that they often shared the deep-rooted pain of disability and questioned why such an unexpected thing happened to them only. A respondent said *a cousin of mine once misbehaved with me and verbally abused me "orey kuntodaa, nuvvu emi cheyalevu ra"* (hey crippled, you cannot do anything) [Aditya, 8 years old].

The other experiences of body shaming are reported by several respondents. *My friends humiliated me on the basis of my gait as I swing like a duck* [Tarun, 25 years old]. This kind of experience in interaction is intimidatory leading to loss of self-esteem. *Most of the time, I keep thinking about why God has given me such a pitiful life* [Pravallika, 18 years old].

Parents of the respondents reported that their children used to dream about becoming normal one day as they used to work hard to get back their impaired body to normalcy. Parents reported that their children were ready to sacrifice everything they had. *I took my child to an astrologer who said due to the past deeds she was born impaired in this birth. He advised that by performing pujas (a way of worshipping God), Homams/Havans (rituals doing in front of fire God) as a penance to compensate the past misdeeds so that Gods will be satisfied and my child can get back to normalcy. My daughter was very excited to do all those rituals including forty-eight weeks of complete fasting very religiously. The rituals costed us around thirty thousand rupees but I couldn't notice much difference* [Hema's Mother].

Coping Strategies

All the family members and parents of the respondents recollected that they had feelings of trauma, guilt, apprehension, and depression when their child was born with impairment. They recollected that they had never expected that such a thing would happen to them. They could not recall any family history or hereditary cause that could have resulted in the impairment. Most of the parents opined that the probable reason for the disability of their children might be due to consanguineous marriage. In the case of non-consanguineous marriages respondents are connecting child's impairment to their fate (*thala ratha*), their *karma*, the result of their past misdeeds, their sins (*poorva janma paapam*). A parent recollected saying *I remember my son was born with twisted hands and legs. I don't understand why he got this impairment. My husband is neither a close nor a distant relative to me. I met my husband through a matrimonial agent. As far as I remember no one in our family has got any impairment, including my husband's side* [Tarun's Mother]

In our family, there is no family history of any impairment. Had that been the case then my elder son would also have a defective limb. But he is perfectly normal [Niharika's Mother].

When I trace back to my family history, no one is impaired from both sides but both my children are disabled. The probable reason could be that… I'm married to my cross-cousin. My husband is educated and I'm educated, when doctors questioned us why we have sinned by marrying a person of the same descendent I had no answer [Akhila's Mother].

I know cross-cousin marriages are not good for our future generations, but what to do when my father is not able to pay huge amounts of dowry to an outside person other than my cousin. My father's sister's son said he likes me; both my father and my aunt happily accepted his words without listening to mine. Now our entire family is suffering and spending more on my child's health than dowry [Nisha Gopika's Mother].

Parents tried to cope with the impairment in their children in different ways to minimize the stress. For instance, among the respondents, a majority of the mothers believe that seeking emotional support through faith in God was one of the strategies adopted for managing the stress. Others took solace in the belief in *karma* of the previous birth. They opined that discharging God's duties sincerely would enable them to cope better. It gave them the moral and emotional strength to overcome anxiety and apprehensions that were striking in their everyday lives. Some of the parents reported that *we have to accept the fact that it might be the*

result of our karma in the previous birth, so we will have to discharge our duties sincerely in this birth. God is wise; he gives this kind of situation to test our patience. This is God's wish and he has written it in my daughter's fate. My wife is always worried about her future. I always say to her, "when God has created a problem, he has a solution too" [Nisha Gopika's father]

There is a Telugu saying "runanubhanda rupena" which means that our relations in this generation are a continuation from the previous birth. In the previous birth, my daughter must have done a lot of service to me, in this birth my daughter is borne with impairment so that I repay the service to her which she rendered to me in my previous birth. When the concept of repaying debt becomes equal then my daughter's condition will become better [Akhila's Mother].

My Daughter is attacked with polio because I was neglecting to worship our "kula daivam" (caste God). When she was affected with polio, I realized that I shouldn't neglect our kula daivam, he is angry with me and gave me a disabled child. On every pournima (full moon day) and Amavasya (no-moon day), there would be some powerful rituals to follow with our kula daivam. So that, one fine day, God will shower his blessings on us [Anusha's mother].

I pray to God to liberate my child's life for this janma (Birth) and ask God to give her the next birth as a normal child. What else can I do when her father is hardly bothered about her and my other three children won't give her any food to eat. Being a mother to her I can't bear to see her situation at my home [Bhargavi's Mother, No formal education].

Economic Status, Disability and Coping Strategies

The coping strategies varied with the economic status of the families. Families of thirteen respondents belong to well-to-do class category as the parents are well educated and tried using all their resources to find a solution to the problem of impairment. However, irrespective of their economic status all parents have tried their best to find a cure or treatment to the disability of their child by approaching state schemes like Arogyashri or CM's reliefs fund and so on. Most of them made efforts by traveling to the nearby towns to avail better medical opportunities and treatment for their children. They tried to make themselves aware by gathering information through known persons, medical camps, non-government organizations, newspapers, etc.

I took my son to the Institute of Medical Science and had his operation done by a reputed doctor in Hyderabad. Going all the way from Achampet (a small town in Mahabubnagar

district) was not that easy of a task for poor people like us. For every review, like, removing stutters, putting plaster, we had to go to Hyderabad incurring lot of expenditure on commuting. However, unfortunately, after the surgery, we couldn't change my son's disabled identity as the surgery did not give us the expected result. Whatever is there in our hands we could do, but the rest is God's wish [Aditya's Father].

We have shown our son to so many doctors in the city. Doctors said they can't do anything as our son was born with deformed hip joint. We continued with the physiotherapy treatment till he was five years old. We have done all that we could, but we couldn't fully get his gait right. However, I'm happy to see him walking without any support. I felt that God is there with us. At times, I feel that as an educated parent we have to understand his situation and should satisfy with whatever we have, we shouldn't expect beyond a certain point [Tarun's Mother].

In some cases, although their child could not get cured or showed no signs of improvement parents didn't give up hope. For instance, Akhila's mother, being a single parent, was struggling to treat her impairment for many years and was still continuing to do so.

When she was born, doctors told me that she won't survive for more than a year. As my daughter is born with multiple disorders like a hunch back, improper nerve function in her pelvis which restricted her movement in walking, a hole in the heart, led to development of small lungs with limiting breathing capacity due to which she had a severe breathing problem. Now she turned fifteen years old. She underwent a total of four surgeries. I hope to see her better after one more surgery, which the doctors have now suggested [Akhila's Mother].

A few families who were financially constrained had very little access to resources or facilities and discontinued the treatment they were giving to their children. They could not cope with the frequent medical visits to the city due to high expenditure on commuting. They were so poor and realized that without money nothing was possible, they had no other option but to accept their child's condition as their destiny.

After my daughter's corrective surgery, I couldn't see much improvement. The doctor told us that we need to undergo physiotherapy. My daughter says physiotherapy is very painful. When we went to the physiotherapy department, they told us to come to Institute of Medical Science (IMS) regularly. As we stay in Raajendranagar, we can't come regularly. In IMS, surgery is free of cost but not for physiotherapy treatment. Doctors at IMS suggested to look for a physiotherapy clinic in Rajendranagar, near to our home. Physiotherapy in IMS is very

expensive. We cannot afford Rs. 300-500 for each physiotherapy session. When we explained our problem to the doctor, as an alternate arrangement, they told us to practice some exercises at home. She has stiffness in her leg and we are unable to get those moments back. We don't have any kind of support from the government for physiotherapy treatment. I thought my daughter will be perfectly alright after the surgery and we thought of getting her married. But I couldn't see any improvement due to lack of physiotherapy. We were very sad… but then we prayed to God and kept quiet, what else could we do? She is our daughter, we gave birth to her, and we cannot throw her away despite having one more daughter. Whatever is written in our destiny… I have accepted it as a financial constraint. Otherwise, don't you think that she would be alright…with money everything can be in the right place. I don't have money, so…being a mother I can't do anything for her [Aarthi's Mother].

When the facilities were within reach, even economically weaker families made sincere efforts to cure their children. However, on reaching a point when the parents felt that they can't afford the treatment the child is left to destiny, fate, *karma*, etc.

My husband doesn't look at Bhargavi at all. For him she is an unnecessary burden on the family. My other three children also feel the same. At my home, Bhargavi is like "paniki rani vastavu" which means… she is like a useless object. *At my home, no one treats her with minimum humanity. No one bothers whether she has eaten or not. At home, other than me, no one feeds her. I feed her before I go to duty and feed her after coming from duty. In the meantime, even though she screams out of hunger or thirst, no one bothers about it. At times, I wonder why God is still keeping her alive and punishing her when no one cares about her. Being a mother, I can't stand to see her pain and at the same time I feel I'm helpless for her and can't be thrown just like that. I'm a mother, I've got a bond with her* [Bhargavi's Mother].

Family, Peer and Kin Support

Parents of the respondents reported that the care and treatment needed and given to children varied with the type and the degree of the disability. Persons with locomotor disabilities undergo multiple phases of physiotherapy, dressing (in case of wounds), stutter removal, X-rays, massages and frequent medical check-ups during pre and post-surgery. In case of corrective surgeries, they are bed-ridden for a long time. Doctors suggest for the use of calipers, crutches, tricycles, or wheelchairs, depending upon the need of the person. Wheelchairs and crutches are still used by some of the respondents. In the initial years, the total medical expenses

varied between three thousand to five lakhs. Subsequently, the expenditure on medicines comes to about thousand rupees per month.

We used to spend more than five thousand rupees per month when we took him (her son) to Hyderabad for treatment which included medicines, physiotherapy sessions, and buying orthotic devices like calipers. In addition, we had to spend on transportation. At the age of seven, doctors have operated on his both the legs. Now, he is able to walk without support. But he cannot walk like us. Five lakhs have already been spent since he is born. We even sold a piece of land in Achampeat (their native village) for fifty thousand rupees and took a thirty thousand gold loan for his treatment, the operation was done under Arogyashri scheme. We could not afford further treatment like physio, and then some regular medicines. [Aditya's father].

*When my daughter was hospitalized for corrective surgery, we took a gold loan by keeping the ornaments with a marwadi (*who gives money by taking gold as collateral security without any documentation*) in our village, Rajendra Nagar. I had one younger daughter, no relative or anybody came to stay at the hospital or look after the younger daughter at home. In the hospital in Hyderabad, we did not have anyone to help us during the treatment of our child* [Aarthi's Mother].

We are not residing in Hyderabad. We have to come all the way from Karimnagar (about 150 kms away from Hyderabad), which is not that easy. I also have two kids. Whenever I come, I've to keep my children at my neighbor's place. None of the family members or relatives extended their help as ours is a love marriage. At times I feel like giving upon the idea of further treatment to my son [Anil's Father].

The role of neighbors and relatives is not very encouraging in the case of several respondents. Parents of the respondents observed that they can depend neither on neighbors nor on relatives when it comes to treating the disabled child. It is found to be very difficult if the parents have got into wedlock through love, inter-caste, and inter-religious marriage.

It was found in the study that, over the years, a majority of the parents, both from rural and urban settings, had given up hope in finding a cure to their child's disability. They couldn't continue their child's treatment due to various reasons like financial constraint; their younger children not taken care of by the extended families, not being able to travel to distant places for every visit, lack of affordable public transport, lack of proper washrooms, etc. Parents observed

that they made sincere efforts in getting government schemes for support and aspired for better future prospects. However, only a few parents could access these government resources and some of the parents could not access the government resources due to lack of awareness.

I have no idea of where to get or whom to approach for the income certificate, disability certificate, and aadhar card. I came to know about the disability certificate after approaching IMS-ALMU for my son's tricycle [Father of Anil, 6 years old].

In the case of unmarried women, parents sought financial assistance from the government desperately.

My parents are unaware of the government schemes/provisions and are desperately hoping for some financial support from the government. They came to know about disability pension very recently when they came to submit my disability certificate at IMS-ALMU for my caliper [Anusha, 19 years old].

Family Expectations and Support

Family members such as parents, siblings, and their children (in the case of married women) were asked about the expectations they hold for the persons with disabilities to understand how they plan for their future and the importance that they attach to the social institutions of education, marriage, family, roles, responsibilities and social relationships. Parents of the fifty-two respondents (eight respondents are married) expressed more concern about the diagnosis, detection, treatment, or cure of the impairment when their child was young. As time passed by there has been a shift in focus from cure/ treatment to plans for the child's future through higher education, job, and marriage.

All the parents or elder siblings, regardless of their socio-economic status, want their child/siblings (regardless of impairment or gender) to access higher education. Eventually, they aspire for a good career that would provide financial support and social security to them. Hence, they were trying to provide all the necessary support to their children and siblings in terms of the facilities needed for their education. They were more concerned about their safety if the child or sibling with a disability is a girl. For instance, some parents wanted their girl child to complete their graduation and take up some government jobs so that she would be financially secured.

In the future, I want to see Akhila as a professor in one of the reputed universities [Akhila's Mother].

I wanted my sister to complete her graduation, and then probably she can be placed into some government job so that she feels confident in herself [Harini's sister].

Parents of the respondents who are more educated and from urban and semi-urban backgrounds seemed to be more aware and keener to understand their child's interests. They also made efforts to encourage their children in extracurricular activities like music, dance, and higher studies. Education of the parents apparently is directly correlated to the encouragement given to their children, whether higher education or extracurricular activities.

My mother often asks me to participate in extracurricular activities. My mother speaks to the teacher and tries to see that I'm part of my school's annual day celebrations. I remember that for one annual day celebration, I participated in dance as Krishna in a wheelchair [Akhila,15 years old].

I'm looking forward to entering into disabled sports (Paralympics, Olympics) as my career option [Pranay, 28 years old].

I used to go for self–defense classes like karate (a form of martial arts) before the accident. I hope I will continue to do so after I recover [Prathyusha, 25 years old].

I'm aspiring to do my Doctorate of Philosophy in Economics and Finance from London School of Economics and thereafter get into teaching profession in a reputed university in India [Tarun, 25 years old].

A few parents wanted their children to concentrate on studies but not on extracurricular activities. According to them, investing in education can yield them better results in career options but investing in other fields such as music, painting, etc. may not result in career options in the future. Most of the children felt that they are often discouraged from the things which interest them the most.

I love painting; whenever I paint my parents think that I'm wasting time unnecessarily, I always tell them that it is my hobby, despite that they don't encourage me to paint, they do not wish to know about my interests [Niharika, 10 years old].

I have a passion for music, but my parents don't want me to proceed with my training in music [Nisha Gopika, 23 years old].

The children with disabilities may have reported higher satisfaction if the parents would have encouraged them in other fields such as music, painting, dancing and sports as serious career options.

However, very few parents were happy with the educational facilities provided at school as they had several complaints because they were placed into regular schools. They don't have many options for special schools, unlike visually impaired students. Schools were at distant places which added expenses on the travel. They could not use public transport which compelled them to invest in private transport, and their educational institutions were not disabled-friendly. Expenses on tuition fees and annual school fees were higher in private schools. Parents also reported making a sincere request to the teachers to make special arrangements for the children within the school, but the teachers were uninterested. When all their efforts were in vain, then they decided to drop out of school.

She has dropped out of her school as the school building is not disabled-friendly [Niharika's Mother].

Disability and Marriage

Marriage was emphasized by twenty-nine (twenty-five women/girls and four men) out of fifty-two respondents' parents. Parents want their children to establish their own families through marriage. Most parents from rural background felt that getting married makes their daughter/son socially secure. Parents felt that they could then take care of themselves and their partners. The appearance of a female child with locomotor impairment was a matter of great concern for parents. At one point, parents felt that the treatment of their children is very important so that it should not affect her future prospects of marriage.

A woman irrespective of her disability and education should always have to bind to household chores. What is the point in educating the girl child more? "Kunti pilla ni evaru pelli cheskuntaru amma," which means, "who will marry a girl who cannot walk properly?" They further state that "a*ada pilla ki pelli chesi katnam ichi pampichali. Ade pedda badyata. Aapaina tanu sarigga nadvaledu, daanki dabbulu karchu pettali, inka chaduvu ki karchu pettadam maa valla kaadu."* This means, "being a girl, their main motive is to get their daughter married to someone by giving dowry. This itself is the biggest responsibility. On top of it, they have to

spend money on her treatment. So, investing in her education is highly impossible for them" (Anusha's mother).

"*I am suffering from polio in my right leg. I have to use hip-knee-ankle-foot orthosis. I feel quite uncomfortable while using this device. I always feel that some additional part is attached to my body. When I wear that, it gives support for my legs. It assists in my walking and improves the gait pattern. But the device I'm using is very long and it has to cover from my hip, so I have to wear it inside my dress. I have to wear this all the time when I go out. I have to face problems like sweating, irritating, and so on. Due to this, I have developed rashes on body parts. When I want to wear the device outside my dress, my mother always says that it doesn't look good. My mother often says that I'm unmarried and yet to be married so I can't go out as I like. My parents wanted me to undergo corrective surgery to remove this device permanently* (Anusha, 19 years old).

We have to do something better for her before her marriage - let us see what happens after corrective surgery (Niharika's Mother).

A few respondents, irrespective of gender, opined that getting married is everyone's dream, but somehow (due to society's influence) they felt that the presence of the disability had shattered their dreams.

I was crushed by my friends' words and wanted to go for corrective surgery. My friends humiliated me that no girl will ever wish to marry me as I look different (Tarun, 25 years old).

I always dreamt of a beautiful life about becoming a teacher and having a good married life. After my accident I was hopeless about my dreams and future, now I only think about my independent life in terms of walking and doing daily tasks regularly that I used to do earlier. My relatives, including my parents, are criticizing me that no person will ever come to marry me; I've to be a spinster throughout my life. They believe that for a woman other than a husband no other person will be there to support throughout her life. All my family members curse me that, one day I will be left all alone without anyone to look after me. Because one day both my brothers will be getting married and they will have to look after their own family needs. Before the accident, everything was quite normal for me. After the accident, I'm seeing the dark side of my life; I was not used to seeing such a phase in my life. I felt I was lost in the forest alone and couldn't find a way out. All my dreams were shattered (Pravallika, 18 years old).

One of my aunts told me that if I'll go to the temple religiously and perform some ritual (Abhishekam- a sort of ritual to God, where people bath the God idols with water, milk, curd, ghee, sugar etc.) for lord Subramanyam Swamy on Tuesdays, I'll get a good husband despite my impairment. I started this when I was twenty-five years old, now I'm twenty-eight. I'm continuing this for the past three years, but I couldn't notice any result. Still, my parents insist I go to temple. They say that none of these rituals go waste and should wait till time comes. The most annoying thing is with the priest. After the abhishekham he blesses everyone who does this pooja. I've seen most unmarried women and men come and perform this pooja. For everyone, he blesses that "Sheeghrameva Kalyanam Praaptirastu" which means that 'marriage may happen soon'. For me, he blesses "Sheeghrameva Udyoga Praptirastu" which means that I should get a job soon. He always stresses the point that I have polio; I'm handicapped so this blessing will help me. My parents said to the priest to bless her "Sheeghrameva Kalyana Praaptirastu" but he simply ignores us. At times, I ask how will God listen to my prayers of getting married when the priest is not listening to me? I felt that I've to give up the dream of getting married (Hema, 28 years old).

A few respondents felt that their marriage or child's marriage is an unwanted topic. They opined that marriage is just a part of life. Life is about more than getting married.

A typical Indian parent always sees marriage as a settlement in life – I don't know whether this is true. A person always thinks about society, just for the sake of society people will marry off their children irrespective of not finding suitable alliances for their daughters. For me, her marriage is an unwanted topic; I'm least bothered about what others might think of me or my daughter. I'm close to one of the Kakatiya University professors; she is unmarried and according to society, she is fit for so-called marriage but she doesn't want to marry. She says marriage is purely a personal choice. As an educated person she contributes to society in many ways. Her words inspired me a lot. In the future, I want to see Akhila as a replica of that professor. I will be very happy if Akhila becomes a responsible citizen and becomes a mother for hundred children or so rather than becoming a mother for one or two (Akhila's Mother).

I am worried about what others' think of me. I didn't like it when people paid attention to my leg. I felt embarrassing to show my stump to others. I knew most of them might not accept my appearance after amputation. I'm not worried about my marriage, and I don't like others discussing this subject. For an amputee, the main objective would be how to rebuild confidence in oneself rather than marrying and depending on others (Prathyusha, 25).

A few parents of the respondents felt that as their child was too young and was studying, they could not think about their child's marriage. Giving good education to their children at all cost was their immediate target and they felt that it is a necessity, irrespective of their economic status.

I haven't thought about marriage of my son as he is too young. Let him study first and then settle down. The rest we will think later. As I'm not educated, I gave the responsibility for my son's future to my brother who is working as a lecturer in government junior college (Aditya's Mother).

We haven't yet thought about her marriage. We are unable to afford our daughter's treatment. If we were educated well and had a good job then we would have given our daughter good treatment. At times we feel that we are not good parents because we are unable to fulfill our child's desires. We have decided that we will give her a good education first. At times, we feel that our responsibility is to pay her school fees. Our relatives tell us to save money for her wedding instead of spending money on her education. Marriage will happen after twenty years. They scold us that irrespective of our economic status we are sending our daughter to private school. We realize that giving her good education is more important than thinking about our daughters' marriage (Anusha's Parents).

The physical appearance of the girl child with locomotor impairment is a matter of great concern for the parents. At one point, parents felt that the treatment of their children is very important so that it should not affect her future prospects of marriage. There are instances reported by respondents where doctors suggested going for corrective surgery before a girl's marriage.

Akhila's orthopedic surgeon often tells us that their team will do the best in improving her posture before her marriage (Akhila's Mother).

In this context, one of the doctor respondents says that -

When patients approach us, we think from two perspectives, if a woman approaches us, we think from a different angle that we should do our best before her marriage because we think that in the future people should not point out her appearance. So, we try our best to improve their functionalities and posture before their marriage and we tell their parents that these many months or years may go by in their child's treatment. We should understand parents' concerns as well. If a man approaches us, we ask them whether he is married or not. If he is married,

then we become more cautious because we assume that he is the breadwinner of his family, and his family is dependent on him. In the case of an unmarried man, we don't think much about his appearance. As we are being driven by the notion that men are the breadwinners of the family and any girl can accept him as a husband. As a doctor, we are not supposed to think about these distinctions, but we are compelled to think in this way [Dr. Raju Ayengar, Ortho Surgeon].

For some parents, marriage was important for future social security. But the notion of social security in the case of marriage among parents is changing with respect to time and a few parents are leaving the decision of marriage to their children. While some parents (twenty-five) planned for their children's marriage in the future, very few parents (ten) left the decision to their children regarding marriage, and others (seventeen) shared their apprehensions about marriage. Parents reported to be worried about non-acceptance, abandonment, neglect by the husband, and in-laws after marriage. As a result, they were skeptical about it. A few parents opined that if the spouse also has a disability, then it is a 'double-problem' for them as well as their children. They believe that disabled couple cannot take care of each other and then their children. Despite this, most parents considered marriage as a social necessity and social security because they believe in the concept of establishing a family and social support associated with marriage.

In this context the responses of the parents were:

As far as marriage is concerned, do you think anybody will get married to a person who limps and looks different? Normal children will never sacrifice so much to marry disabled women. And if both of them are impaired, how will they help each other? That's the reason we are spending on her treatment within whatever little we have. So, a normal person can come and marry her (Anusha's Mother).

In the present-day society, even after taking loads of amount as a dowry, the wedding is rarely turning out to be successful for non-disabled women. Imagine then, "who will marry my daughter when she has an artificial limb?" (Pravallika's Mother).

Pranay, 28 years old says, *I won't get married. If the girl forsakes me or leaves me in the middle and goes away, then what will I do? How will I manage? Instead of that I want to focus on my career and want to lead my life with dignity.*

We want him to get married to a girl who is not disabled. His condition (pausing for a while) would have been much better if he didn't meet with that accident. So, if the girl is also impaired, then how will they manage? (Pavan's Mother).

Parents of girls had various inhibitions and fears about pregnancy, childbirth, and motherhood. They were also concerned about the pressure of household chores and heavy domestic responsibilities attached to marriage. The fear of the impairment being genetically transmitted to children also dominated the minds of some parents and children. They felt insecure about in-laws who would consider disability as a stigma and burden and ill-treat them.

I want my daughter to get married but she refuses. She is scared that her spouse and in-laws might not treat her well. She worries that if he leaves after the marriage, where will she go? She is also worried about her pregnancy. She worries that, "when I'm unable to take care of myself then how can I take care of my children?" She says, "One question which haunts me in getting married is my treatment which is a long–term and an ongoing process. What to do after getting married if my husband gets irritated by the costs incurred in my treatment?" (Pratyusha's Father).

On the other hand, while expressing apprehensions about marriage, a few parents have opined that if their own family members couldn't understand their children's disability, outsiders would be even less likely to. A very common practice in both Telegu states is marrying a cross-cousin. In this context, parents have felt that if their kin group is refusing to marry their disabled children and were failing to extend their support, then how could outside families support them? This was reflected in their responses.

My daughter has two cross–cousins. When my daughter was born my mother-in-law said that either of her cousins will marry her. She was diagnosed with polio at the age of two and was unable to walk properly. Then everyone at our home was silent. They are not at all bringing the topic of marriage in front of us (Aarthi's mother).

I was in love with one of my cousins since childhood. Both our families have been brought up like that, so we assumed that both of us are made for each other. Things were quite normal before my accident, after I met with an accident my cousin left me all alone. I thought she is my life; the person who is supposed to support me in the most difficult times of my life has dumped me in between (Pranay, 28 years old).

Respondents' parents who belong to low-income group with little formal education (twenty-five out of fifty-two) reported that they were forced to compromise on the issue of a child's career or marriage. These parents shared that they were unable to plan for higher education as they believe that getting their children married is the most important thing than giving them a good education or a well-paid job. Though they wanted to give them both, their financial status does not allow them think about the child's career or education. They mentioned that, at times, for basic necessity they have to take a loan from money lenders as their income is unable to meet the requirements of necessities. For them, investing in education is beyond their means. However, the issue of marrying off their children was one of the top priorities for them. It was more evident in the case of parents whose daughter was disabled.

As long as we are there we look after our daughter very well. But there should be someone who will look after her after us. If she establishes a family then her husband and in-laws will take care of her. How long we can stay with her? [Anusha's Father].

Though my daughter studies well she won't get a good job because there are lakhs of more educated people, non-disabled and still they are jobless. Then why will the government give a job to a disabled daughter? [Pravallika's Father].

This shows that the ignorance of parents about the value of education can make them insensitive in knowing the advantage of education for getting a job which would help their child to lead a financially independent life in a dignified manner, rather than getting married to someone else and depending on them forever.

On the other hand, out of eight married respondents, two women were disabled after their marriage. Surprisingly, in contrast to the opinions of the non-disabled persons about the marriage of their disabled child, three married women and one married man, who are disabled, expressed happiness about their marriage despite being disabled since childhood. They were quite happy with the present relationship and were happily leading their married lives.

I am suffering from polio. People used to degrade me that I wouldn't get married at all. I was least bothered about what others are talking about in front of me or at the back of me. Despite being disabled, I used to participate actively in all the village events and I was engaged with Anganwadi center at my village. I was very much blessed when my husband entered my life. My husband, who is a non-disabled, is sensible and understands the pain of the disabled. When my father–in–law lost his leg in an accident my husband did a lot of service to him. At that

moment, he decided to marry a disabled woman and I was the fortunate one to marry him. The only annoying thing about my husband is that he pampers me a lot and he doesn't send me out. He always asks me to take rest at home. He always says that- I've worked a lot before my marriage now it is his responsibility to take good care of me (Kalyani, 29 years).

I lost my leg in an accident when I was 18 years old. Then my mama (a cross-cousin; mother's brother) used to do a lot of service to me; like, he used to lift me up while taking me to the hospital, did a lot of dressing to my stump, then he thought that other than him no other person will understand these problems and he decided to marry me. Despite I liked my mama for understanding me very well…I was like…I don't want to marry my mama and spoil his future by doing service to my entire life. I told him several times not to marry me out of sympathy that no one will marry me. He didn't listen to my words at all. He was very committed to our relationship. Except for me, he didn't like any other woman. I'm blessed to have such a wonderful person in my life as my mother's brother first and later on as my husband. I'm also blessed with a baby girl (Sabitha, 35 years old).

I'm suffering from osteogenesis imperfect (presence of completely deformed bones and muscle weakness). Due to this condition, I crawl. I completed my graduation and now working in a bank. On the other hand, I have two beautiful non-disabled sisters, one has completed her B.Tech. and the other one is pursuing her intermediate. I was married to my cross-cousin (father's sister's son). When my cousin proposed to marry me, my parents told him to choose anyone out of my two younger sisters because they opined that in the future, he shouldn't regret our relationship after marrying me. He was like- anyone can marry my two younger sisters. He said, "being her cousin, I should be able to understand her completely. If not me who will understand her"? He fought with my aunt and uncle and married me. I was blessed with two non - disabled sons, after giving birth to two non-disabled sons my own aunt and uncle have accepted me as their daughter-in-law, now I'm leading a happy married life with a very supportive life partner (Priya, 28 years).

When I proposed to my mother's brother's daughter, she immediately accepted my proposal happily despite I was suffering from polio. She said to their family members that a person cannot be judged based on his/her physical appearance. In order to understand a person, one should understand his/her inner self. What if a person is good at his/her looks and not good at understanding things? All my family members, and her family members were convinced by her

words. And we both are happily married. Now, we are happily blessed with a baby boy (Surya, 35 years).

These reflections from few respondents show that, marriages between a disabled person and a non-disabled person do happen and the partners live happily. It appears that parents and the significant others have apprehensions on marriage about their disabled children which may not be true. It may be observed that if spouses are empathetic, then the marriage relationship in the case of disabled women and men is happy. In these cases, it may be found that the immediate cousins are supporting them. This shows a positive insight towards the institution of marriage in the context of disabled people. Thus, the stigma attached to disability and marriage is slowly reducing over a period of time.

On the other hand, nine out of fifty-two parents who were more educated and economically well-off sounded more confident. Where both parents were working and had the necessary resources and social capital, they extended all the support to their child. They aspired for social security through marriage, after the child settled with a rewarding job. They seem to be more aware and were constantly making efforts to brighten the future prospects of their children. Out of twenty respondents belonging to the middle-income category, eighteen respondents' fathers were well educated and were government employees, and they could support their child's career as well.

Two respondents' fathers (out of fifty-two) were of the opinion that even though they wanted to give their children the best in all aspects, their economic condition would not allow them to do so and they felt that they were quite helpless.

The study thus finds that, parents face numerous difficulties in bringing up a child with a disability. As mentioned earlier, if the child with a disability is a girl, the fear and anxieties double. The ability to provide access and resources to their children also varies with the socio-economic status of the families. Despite this, most of the parents sounded a positive approach in their attitude towards their disabled children. The dreams of the parents are on expected lines and the high aspirations that they hold for their children also help them to cope better with their stress and anxiety. The qualities highlighted by parents show that they consider their children with disabilities just as capable and talented as anyone else. This is reflected in the voices of a few parents.

My son is good at academics, He always scores more than ninety- five percent in all his exams, and he always tops his class. He can do most of the physical work. He likes playing badminton. He goes to the gym. He jogs for half an hour every day. He has won various prizes in extracurricular activities like debates, quizzes, essays, and elocution. He also drives a car. I still don't understand in what way he is disabled? (Tarun's Father).

My daughter is a brave girl. She is good at painting, reading, writing, and singing hymns from Bhagwad Gita. She has got numerous certificates in singing Bhagwad Gita and calligraphy. She remembers all our relatives' phone numbers. She participates in most of the extracurricular activities. She dances occasionally in the wheelchair (Akhila's Mother).

My sister is good at her studies. She is very intelligent than me and my brother. She used to top her class. She is a wonderful cook as well. She cooks awesome Hyderabad biryani within half an hour. She is even good at managing household chores (Pravallika's Brother).

Thus, irrespective of the physical, mental, and financial burden, parents, siblings and family members, including spouses, use various tactics to cope and to provide emotional support to their disabled children, siblings, and spouses. They share an optimistic relationship with them and try their best to help their children, siblings, and spouses to lead an independent, purposeful, and successful life. From these narratives, it is pretty clear that sibling relationships are cheerful, spouse relationships are pragmatic, and the institution of marriage seems to be reasonable for married disabled people and family bonding is likely to contribute to the construction of a positive social identity among these persons with disabilities.

The extent to which family expectations and support systems have helped in the construction of a positive identity in persons with disabilities, in terms of their own experiences within their family, social networks, peer groups, and social relationships is discussed in the following section.

Family and Social Relationships: Reflections of Persons with Disabilities in the Construction of their Social Identities

Perceptions of respondents with disabilities were analyzed to understand their emotions, feelings, and experiences concerning their families to get an idea about how self-identities of persons with disabilities are formed through relationships within family, groups, and with their significant others. Over a period of time during the course of interaction with the researcher, the respondents opened up about their close association with their own family members. While

twenty-six out of sixty respondents said that they loved their fathers, majority of the respondents; twenty-nine out of sixty, loved their mothers; and twenty-six out of sixty respondents loved their both parents. A few respondents, fifteen out of sixty, loved their grandparents too, for extending emotional support whenever they needed, in the absence of their parents. Fifteen out of sixty respondents, liked their siblings for supporting them in activities like academics, playing and helping them whenever they wanted. A very few respondents, five out of sixty, liked their spouses too for standing beside them like a pillar of strength and support extended during their hard times and for being with them for the rest of their lives. In the case of married persons with disabilities, two out of eight, liked their children for assisting them in managing their daily chores by sharing their work.

Table 4.5: Respondents Reflections on the Support Extended by the Family Members

Support needed by the respondents	Family members	No. of respondents		
		Men	women	Total
Most liked member in the family	Father	20	06	26
	Mother	05	24	29
	Both	09	17	26
	Grand Parents	02	13	15
	Siblings	03	12	15
	Spouses	04	01	05
Support provided for academics	Parents	24	10	34
	Grand parents	00	01	1
	Siblings	04	07	11
	Spouses	00	00	00
	Tutorials	15	08	23
Support provided for other activities (like going to school, dropping at the school, cleaning themselves, etc.)	Parents	27	32	59
	Grand – Parents	09	07	16
	Siblings	13	06	19
	Spouses	01	04	05
	Children	00	01	01

Majority of the respondents opined that their mothers encouraged and provided emotional support to them during their toughest times. It was reported that most of the mothers paid attention to their disabled children very patiently. Mothers provided their children a stable, caring, loving and peaceful atmosphere at home. Children felt comfortable discussing issues related to their impairment, abilities, peer groups, social networks, marriage, future ambitions and dreams with mother more than father. Those who loved their fathers had expressed similar feelings.

I love my mother most for giving me such a beautiful life. She broke-up her relationship with my father to bring me up in this society like any other child. She often consoles and convinces me whenever I'm low. She always motivates me and gives me a positive outlook toward life (Akhila,15 years old).

I'm blessed to have a wonderful father in my life. He gets me everything before I ask him. He supports me during my most difficult times. He is always there to lift my moods up through his words and with a supporting hand whenever I felt low, or depressed. He often says that life is a game; winning and failures are part and parcel of this life (Niharika, 10 years old).

A very few respondents who did not like either of their father or mother, or were scared or felt restrained to share their feelings with them. In such cases, to express their feelings to both the parents, they used to share with either of them and they were treated like mediators to convey the message to the other one.

We sit and talk for long hours, my mother, sister, and I enjoy ourselves together. I share everything with my mother that my friends share with me including nonsense stuff like dating boys. We do not include our father as we are scared of him. Whenever I need pocket money or extra money, I often use my mother as a mediator between me and my father (Padma, 20 years old).

A few respondents who loved both parents have expressed their feelings fearlessly in front of both of them.

We eat together, on weekends we go for dine-outs and watching movies. We all discuss and take important decisions together. I can express my views on everything from academics to about the person that I want to get married to in front of both my parents (Tarun, 25 years old).

Fifteen respondents said that they loved their siblings as they could discuss issues about marriage and disability with them. Another fifteen respondents opined that they love to share everything with their grandparents about their insecurities in life. They said that they don't want to see their parents in a state of despair as hopeless and helpless while responding to some of their questions and apprehensions about life.

I love my sister. My sister helps me out from schoolwork to doing my homework to getting most of the things done at home. While we sleep, we discuss issues about marriage. I often ask my

sister whether a nice, loyal, understanding, and good-hearted person will come to marry me (Aarthi).

I like to share things with my grandparents, especially with my grandfather, as I spent most of the time with him. I often ask him philosophical questions like: is marriage necessary for a person? What happens if a person is not married? Why don't people take it for granted that marriage is purely a personal choice? Why can't a person lead her independent life without bothering about so-called others or society? My grandfather calls me with a nickname called question bank (Akhila,15 years old).

Almost all the respondents liked spending most of their time at home with their immediate family members. They love to eat, discuss, watch television and movies, and have a fun time together. They felt that parents were the ones who love and understand them and can know their feelings from bottom of their heart. At times, they even felt that their parents have already studied their minds.

More than half of the respondents, thirty-two out of sixty, are now able to manage their daily chores all by themselves. As mentioned earlier, parents, grandparents, elder siblings (especially sisters) helped in their daily chores during the early years of childhood. Elder brothers helped them in managing tasks outside the home like dropping them at school, college, taking them to the hospital for reviews, etc.

Despite this, at times they did feel that some of the spaces like the living room or kitchen were not accessible to them within their own house. Accessing public spaces in the cities is even more difficult than in rural areas. It is not only about getting into public transport and public buildings; even getting onto the public roads due to terrible traffic in cities can be a challenge. No one can assure you of what happens in the next few minutes while using a public road.

Nowadays, crossing the road is like an achievement, even for non-disabled people. Imagine the plight of the disabled people, generally, who can't run on the roads like non-disabled people. What about the assistive technology users like those who are using wheelchairs, crutches, etc. Though metros are disabled-friendly, getting into metro stations requires a mode of transport one has to use. Metro stations are generally located far away from their houses.

Respondents from villages, have complained about accessing public spaces like improper roads- for every two furlongs there would be a stair or steep roads or slopes or ups and downs. At their house, using a washroom is very difficult for them as they have steps attached to their

washrooms. Most of their washrooms are located outside their home, which is a little far away from their home. Most of them have Indian commodes. Using an Indian commode is very inconvenient for persons with locomotors disabilities, as it is difficult for them to do a proper squat.

Imagine the life of a wheelchair user or a prosthetic user to use their washrooms in villages. They have to control their urge to pass urine when no one is available at home to take them to the washrooms. They cannot even draw a bucket of water from the well and they cannot take it to washrooms. Consequently, they need constant help and support from their parents and siblings.

It becomes very difficult for me to climb steps and walking on steep roads with an artificial leg especially in villages (Pravallika, 18 years, a user of Prosthetic).

I can't just go to the kitchen and set the table. After everything is prepared, my husband and my son lift me and take me to the table…. also, we cannot accommodate a wheelchair into our house. Our house is too small to accommodate even our family members, so how can we accommodate a wheelchair? (Saheena Kathoon, 40 years, wheelchair-bound).

As a wheelchair user, I've many bitter experiences, I could always see all barriers in my life. Always, there should be someone to drop me off, and pick me up from school. My maternal grandfather has taken this as a sole duty and he does his job religiously. At times, I wonder why God has given me such a life that I'm always dependent on others… for going to school I've to depend on my grandfather, for going to the washroom I'm dependent on either my grandmother, my maternal aunt, or my mother at home. If I'm at school I've to be dependent on strangers. My mother always tries to see that my class should be on the ground floor so that it is accessible to me…I feel even a powered wheelchair can't help me on the steps. As I grew up, I put on weight, and I don't want to burden my family with my weight. It's not about what others think about me when I use a wheelchair, it is about in India especially in rural places like Warangal you can't be in a wheelchair for a long time because the roads are not disabled-friendly. Why only in Warangal? I often come to Hyderabad for my treatment, we have never noticed Hyderabad as disabled-friendly. Hyderabad is considered to be one of the biggest and developed cities. Look at the roads and traffic; do you think that Hyderabad can accommodate wheelchair users? (Akhila, 15 years old, wheelchair user).

Padma says that when she came back home with a prosthetic limb, she felt things had changed at home. Earlier, she used to feel very comfortable at home. But now she feels that home is a very strange place for her. She recollects, *Coming home, … It was like, well, great to be back home; lovely…. Everything was as it used to be… Great, but then I looked up at the stairs near the main entrance or washroom, I looked and I realized, I've changed. How the hell am I going to climb up them... I was frightful to see them. I could get around in the whole house if only I could get over the doorsteps. I don't understand why my family members haven't yet removed the doorsteps. I often say to myself that only for the sake of me they can't remove the steps. At times, I feel that life has been turned upside down. Everything becomes so difficult, nothing is easy* (Padma, 20 years old).

These narratives on their experiences suggest that that respondents need constant support from the members of the family irrespective of whether they are residing in cities or in rural areas. In cities, residing within the house is an easy task but it becomes difficult and unimaginable when it is necessary to go out. It looks like one needs to have their own transport to go out or either they should always be escorted by family members. In villages, apart from accessing public spaces, residing in their own home itself is a difficult space to stay within.

The Institution of Family and the Identity Formation

A large majority of the respondents were happy with the nature of the relationship that they shared with their immediate family members. Quite a few, fifteen out of sixty, were happy with their extended family members too. Most of them, irrespective of their age, reported that when scolded by their parents, grandparents, siblings, and children they used to get angry. They used to blame God for keeping them alive. They used to tell themselves that God gets pleasure when he sees us crying. Elders with disabilities used to feel a little offended when they were being scolded by their children due to the age factor. They felt that at least they should respect their age. But eventually, they became confident that their family members were ready to stand by them in the most difficult times. Over a period of time, they were convinced that at least one person in their family loved them unconditionally.

In the case of younger children, most of them were aware that their parents felt stressed about their child's future and their responsibilities. The children were very sensitive about their parents. They used to correlate their parent's state of emotions to their happiness. For instance, they were aware that their parents' state of being unhappiness varied with their state of happiness, levels of performance in academics, and extracurricular achievements.

My mother is extremely happy when I'm happy. She doesn't express her sadness in front of me but she is sad when I'm sad and she would be overjoyed if I top my class in exams and my teachers appreciate me (Akhila). Tarun expresses, *my parents are extremely happy and proud of all my academic achievements and extracurricular activities.* Similarly, Pravallika emphasized that *her parents are happy to see her walking again.*

Despite the challenges that their family members confronted, the respondents asserted that most of the time they had never been criticized for their looks or disability. They admitted that parents and extended kin occasionally scolded, could be due to society's influence. However, the respondents also emphasized that parents and extended kin provided all the necessary support in pursuing their dreams and goals.

Coming to the context of sibling relationships; these brought joy, pleasure, and at times pain. Although the respondents had a good time with their siblings when they were at home, rivalry among siblings was also evident on a few occasions. During quarrels, there were instances of siblings criticizing about their disability or even engaging in name-calling. The family members, including parents, reported that siblings, during quarrels, addressed them as *kunti, aviti, etc.,* when they were young. However, they found that brothers and sisters became more sensitive towards the problems of their siblings as they grew older.

My brother teases me that I can't walk properly. He calls me by the name kunti. I feel bad. Now as he is growing up, he has become sensitive and started understanding my problem. He takes care of me very well. At school, if my friends ever tease me on account of my disability, then my brother hits them back (Niharika,10 years old).

At times of conflict between the family and the extended kin, the question of disability and the conditions associated with it becomes central to the discussion. Some reported that negative remarks about their disability were made by their relatives to both parents and people who are suffering from a disability. This caused intense hurt to the family. It appears that at times of crisis there is a tendency to strike at the weakest point. The emotional hurt caused to the disabled people is seen through their expressions like:

When we have occasional disagreements at home within our kin group, our own paternal aunt abuses my parents that they have given birth to a lame child. I feel really bad at such times. I used to feel worthless of my own self (Niharika, 10 years old).

I remember my paternal aunt used to ask me, "Why don't you sit in a corner like an object, when you cannot walk properly? As you can't move your body fast don't you think that you are obstructing my way?" I was pained by my aunt's words (Nisha Gopika, 23 years old).

There was a cousin of mine who told me that, "How can you claim that you can do things on your own when you cannot walk without a stick and you cannot run like me." I felt really offended. None of my family members believed that a cousin of mine criticized me on the account of my disability (Padma, 20 years old).

Participation outside the family

Acceptance of persons with disabilities within the wider social networks is not reported to be constrained. As reported by family members of the respondents, a majority of them attend family weddings, festivals, and ceremonies and were comfortable in going to such places with their family. Majority of them, fifty–one out of sixty, attended religious ceremonies and weddings and a few, twenty–five out of sixty went to family outings. They were comfortable in participating in such events and they felt that involvement on such occasions had helped them to revitalize their thought process and confidence levels. By and large, thirty-two out of sixty respondents recalled that they have not received any unkind remarks from any relatives, extended kin group, or friends during such gatherings. However, a small number of people have been confronted with bitter experiences on such occasions.

Once when I went out to my cousin's wedding with my grandparents without my mother, an aunt satirically reflected, "she has a disability and on top of that she is unable to take care of herself as she is wheelchair-bound." She laughed and said in front of all my relatives – "she always needs two bodyguards to assist her throughout her lifetime. That's the reason her father left her at the hospital, who can tolerate this type of child for a lifetime!" And they said to my grandparents, "who asked you to come with this child? With this child, you don't even get the time to greet the bride and bridegroom, what will you enjoy at the wedding?" I was resentful and was upset at that time (Akhila, 15 years old).

Since I was married to my cross-cousin, who takes care of me very well, people comment negatively that, "I've kept some medicine to my husband, that's the reason my husband won't leave me alone for a moment despite having a disability." I had felt very offended and depressed at that time (Priya, 28 years old).

When I went to my cousin's wedding and was actively engaged in the rituals, my aunt said that, "Don't try to grab others attention towards you by wearing beautiful sari and jewelry, as these people won't fall for you, if at all they fall for you it is just because of your financial status, remember the fact that you cannot walk properly" (Nisha Gopika, 23 years old).

When I went for my cousin's house-warming ceremony, I remember what one of my aunts said, "it is surprising to see you, I thought after your accident you will be sitting in a corner. Oh! Good to see you that you dressed up very well despite losing your leg" (Padma, 20 years old).

A few of them who were very keen on attending ceremonies had certain apprehensions. They expressed their discomfort about confronting embarrassing questions, listening to negative comments, or simply feeling ignored or neglected, or self–conscious of being stared at. Unmarried people with impairment may be more vulnerable to abuse, rejection, and exclusion in social gatherings. Some of the respondents in the study specifically said that they had experienced pain and distress on many occasions. This was evident in the following responses.

Though I feel comfortable attending all the occasions, at times, I feel timid. They ask me a wide range of unexpected questions like – suppose if there is a young lady and an older lady, an older lady would ask questions like "would you marry her?" in front of me. It is so embarrassing to face such questions and situations. That's the reason I avoid going on to such occasions (Tarun,25 years old).

I like going to parties but at times I feel bad when people ask me about my legs, my future, my marriage, etc. (Pravallika, 18 years old).

I'm a very social person. I like to interact with people. I do attend functions and love to participate in all religious ceremonies, but at times I feel isolated from my community when they ask me questions about my marriage. People simply give me advice on my face that "I have to go for love marriage, no other person from our community will understand you or support you. It is better to look for one among your classmates. Since you are educated there is nothing wrong in going for love marriage" (Pratyusha, 25 years old).

It may be ascertained from these responses that the degree of impairment may impose physical limitations, but the pain of disability is imposed on them by others through their comments on the impairment. Mike Oliver 1990 suggests that disability is imposed by society on top of their impairment. The crucial thing to notice is that though many wish to negotiate a normal identity like non-disabled, however, they are often constrained from doing so. Most of the time they

are made to feel that they are not normal. It may be said that society tries to perpetuate a sense of inferiority complex by categorizing them as disabled. The social model that points out that societal attitudes and barriers disable the individual is particularly pertinent in this context.

Most of the respondents are self-conscious about burdening their parents/siblings/grandparents who have to help them when they attend social gatherings by taking them along, by bringing food for them, etc. They feel that they are bothering them. They also feel restricted as they have to sit in one place and need help to move around. For most of them, traveling became inconvenient and also involved expenses. At times, parents compromise in attending parties. In such instances, if there is an urgent need to attend the event, parents make necessary arrangements before leaving them alone at home.

Wherever I go, I have to adjust to sitting in one place as I cannot move around. I also feel that everyone is troubled by carrying me along, bringing food for me, and doing a whole lot of other things…we have to hire a private vehicle which is very expensive and it is also difficult taking me out…we go to religious places because my family members believe that I might become normal by God's grace but we ignore going to social functions and in such cases, my mother stays back along with me at home as she does not leave me alone (Akhila,15 yers old).

At times, my family members find it, really, really, difficult to take me as long as I am unable to move around freely. It becomes very difficult for me to climb steps and walk on steep roads, with an artificial leg (Pravallika,18 years old).

On a few occasions, when I'm alone at home, I'm able to manage and handle things on my own. I sometimes ask my mother to give me things that are out of reach for me (Padma,20 years old).

Persons with disabilities often felt lonely despite being in the amidst of all the family members at home or sometimes when left alone at home. A few respondents reported that they felt like shouting out and crying loud when they were alone in the house. They said that, when lonely or depressed, they adopted various strategies to keep themselves engaged by playing with an infant child, talking to a friend over the phone, listening to music, learning cooking, playing indoor games, tending to plants or by sleeping.

A couple of respondents reported that they do not like to participate in social gatherings as they were not permitted to do so by their parents. Parents were possessive and worried about sending their children to such occasions. Their parents worry because they were little scared of what if

others hurt their children in front of everyone. A few children withdrew themselves as they were not interested to attend them.

Referring to this, a respondent says– *I don't like to participate in family gatherings as I'm not a very social person. I always feel my home is a beautiful place to feel good. Moreover, my parents, unlike other parents, don't insist on me going out* (Pratuysha,25years old).

Instead of going out, I prefer to be at home and am happy to experiment preparing new dishes instead (Padma, 20 years old).

It may be inferred from the above statements that persons with impairment shared strong, secure and close bonding with their immediate family. They were sensitive towards the issue of their family members, especially when the parents were being blamed for their disability. The support and love that they get within the family provided security and confidence to them and this gave them the positive opportunity to develop their personality. The behavior and attitude of the significant others within the family led to the construction of a positive personality and strong social identity in the process of interaction in their everyday life. However, they were hurt when negative comments were passed by their relatives or siblings. The negative comments made them feel more disabled than their impairment. They felt offended when negative comments were made about their impairment, categorizing them as disabled.

CASE STUDIES

The following section presents cases of fifteen orthopedically/locomotor impaired persons depicting experiences in different social milieus implicating impairment and body. The narratives are of their own as well as of their parents and significant others. These narratives present the lived experiences, feelings, emotions and identity construction by persons with locomotor impairment shared with the researcher during the personal interaction.

It may be said that the journey from childhood to adulthood is one of mixed emotions denting their social, psychological and physical being. They have experienced a disabled identity through the process of social interactions with others in their social networks. They reportedly absorbed diverse setbacks, confronted challenges, and struggled to stand on their feet independently and energetically, nullifying the attempts of society to suppress them from time to time. The narratives also highlight the socio-cultural and economic aspects related to assistive technology for orthopedically challenged.

Case 1: Aditya (8 years old)

Aditya is an eight-year-old boy born with congenital *talipes equinovarus*, also called as club foot. He hails from Achampet, a small town in Mahbubnagar district. He comes from an educationally and economically backward family. His father had studied up to class ninth and maintains a bike stand at the railway station earning a meager income of rupees six thousand to seven thousand and five hundred per month. His mother has no formal education. She works as agricultural daily wage laborer earning up to rupees fifteen thousand per month during the crop season. Aditya belongs to the Mudiraj community which is categorized as an OBC (Other Backward Class) caste. He is the first son of his parents.

Aditya described how he spent his early childhood in his town. As he grew up, he identified himself as disabled through the process of social interactions with his own siblings, kins, relatives, a team of medical professionals like doctors and rehabilitation professionals, peers, and teachers. Aditya recalls how doctors associated his disability with the consanguineous (cross-cousin) marriage between their parents. He says that "my father's maternal uncle's daughter is my mother." Aditya was very much influenced by his doctors' words and tells himself that probably this marriage had made him disabled. He recollects that there is no family history of disability in their earlier generations.

Aditya's father tried his best to find a treatment for his son's impairment by seeking financial help from both his parents and in-laws. Aditya's paternal grandparents had about two acres of land. They had taken a loan of fifty thousand rupees on that land and a gold loan of thirty thousand rupees for his operation and further treatment. When Aditya was born, parents noticed that their son was different from others as both the legs were deformed. At the age of two, they noticed that their son was facing difficulty in walking. He couldn't walk without support. Then they realized that they had to do something for their son's independent living. The father took his son to a private hospital in Mahbubnagar town, the district headquarters, for treatment. The doctors cast his leg in POP (plaster of paris) to improve the gait pattern. However, it didn't help him much.

Coming from an educationally and economically backward family, Aditya's parents wanted to give him best education. They enrolled him in the private school in Achampet town. They believed that in private schools he could get better education than in the government schools. However, his school building was not disabled-friendly. He had to climb the steps to reach his

class. Since he cannot climb the steps, his mother used to lift him up to the building to make him sit in the class.

As he grew older, his mother couldn't carry his weight. Hence, they thought that they would approach an expert doctor in the city. At the age of five, they visited the Institute of Medical Sciences (IMS) on the recommendation of a doctor in Mahabubnagar. Initially, doctors at IMS prescribed an orthotic device called 'Ankle and Foot Orthosis (AFO).' They used this particular device for two years. As the device is visible, Aditya's peers, both at school and neighborhood, used to crack jokes at him. His relatives used to give negative comments about him. At the age of seven years, he was operated on both legs thrice in nine months. They first tried to improve the deformed shape of the foot and leg, so that he can balance his body weight on his legs. After the surgery, his gait was improved by 30 percent (as expected by the doctors) and then he was able to walk without the support to some extent. However, his disabled identity couldn't change even after surgery because he is still walking with a limp.

Though negative comments were passed at him, Aditya's parents, along with both paternal and maternal grandparents, were happy to invest money in his treatment. Because they are telling the researcher with a sense of pride that "Maaku manumadu puttadu, Maa Vamshoddhaarakudu vachaadu, maa vamsham ni nilapedataadu, maaku enta karchu ayinaa chestaamu," which means that Aditya's mother has given birth to a son. Aditya being a male descendent of their family, they were of the notion that Aditya will take his family lineage further, hence they don't mind spending money on his treatment and education.

Aditya reflected upon some of the perceptions that he had of himself in interaction with his significant and generalized others. Aditya reflects on how he is viewed by himself and others. He recalls some of his personal experiences in school and family. Aditya seemed to be a confident child holding dreams for his future. There is nothing that he dislikes about his appearance or the way he walks. He adores his legs after surgery because he could walk without support and without using any orthotic device. According to him, he is absolutely normal. According to him "I can't be like others as this is the problem given to me by God. My mama (mother's brother) always tells me that I can prove to others by achieving something in my life. If I become a big officer then people will come to me. My mama says that I can easily become an M.R.O. (Municipal Revenue officer) one of the biggest posts in our village because I have a disability certificate. My mama always tells me to concentrate on my studies. My mama always tells me the advantages of being a disabled child and he often says that my disability

should never be a hindrance to my success. I am doing well at school. I feel good when my teachers and my friends compliment me when I score good marks in the exam." It is very clear that compliments from his teachers, friends, and family reaffirm in him a positive self-image.

Thus, he has no regrets about being the way he is and his disability does not interfere with his satisfaction in doing various things. He is very much influenced by his maternal uncle's words. He also indicates that some people perceive him in terms of his impairment and that this was the reason why they have passed unkind remarks. He says "a cousin of mine once misbehaved with me and verbally abused me saying that I cannot do anything in life as I'm physically unfit."

Aditya also compliments his parents that despite being poor and having little education they tried their best to find treatment for his disability. He looks up to his parents as a source of unconditional love and constant support. He feels proud about his parents as they have given him the best.

Case 2: (Anusha 19 years old)

Anusha is a 19-year-old girl with a case of polio and suffering from severe orthopedic impairment on her right foot. She hails from Kothagudem village from Khammam district. Anusha's father is a farmer who owns four acres of land. She has two younger brothers who are able-bodied. Anusha's parents work on their own agricultural land and have subsistence farming. She belongs to the Munnur Kapu community, an OBC caste. Coming from a poor family with no resources, lack of education and awareness, Anusha received her education till tenth in Zilla Parishad School along with her siblings.

She was absolutely 'normal' at birth. At the age of one and a half years, she was attacked with polio. As her father reported that she had not taken her to polio drops and her mother reports that her father neglected worshiping their *kula daivam* (God, specific to their caste). So, at the age of one and half years, her parents noticed a limp in her walk and brought her to an orthopedic hospital in Khammam town, where the doctors diagnosed polio. The best orthopedics of the town told them that they will operate on her at the age of ten years but they could not get it done due to financial constraints in a private hospital. Though she was able to walk and move around independently, she could not get operated on as her parents were financially constrained. At the age of twelve, at the behest of a suggestion of a doctor in their town, they came to IMS. The doctors at IMS advised her to use a caliper (Hip-knee-ankle- foot

Orthosis) to support her leg for a few years. IMS doctors suggested she should undergo surgery between seventeen to twenty years of age as the bone growth will be more during these years. In the meantime, doctors asked her to use the caliper to prevent further deformities in her leg.

Anusha studied only till tenth class and has dropped out of further education due to her financial condition. She never thought much about her career due to her family circumstances. As her mother reflected, *a woman, irrespective of her disability and education, should always be bound to take up household chores, what is the point in educating a girl child more*. Anusha's parents are more concerned about her marriage rather than her education. They want to correct her deformed leg just for the sake of her marriage.

It is clear that her parents want to hide her disability from significant others. Her parents reflect that "aada pilla ki pelli chesi katnam ichi pampichali, ade pedda badyata, aapaina tanu sariga nadvaledu, danki dabbulu karchu pettali. Inka chaduvu ki karchu pettadam maa valla kaadu". This means, Anusha, being a girl, parents' main motive is to get her married to someone by paying dowry. According to them this is their biggest responsibility. On top of that, they have to spend money on her treatment. Thus, according to them, investing in her education is highly impossible for them. Anusha's parents are unaware of the government schemes/ provisions and are desperately hoping for some financial support. They came to know about disability pension very recently, when they had to submit her disability certificate at IMS-Artificial Limb Manufacturing Unit (IMS-ALMU).

On the other hand, her brothers are still studying and Anusha's parents believe that things would be better after they start earning. They also hope that the government can provide them with financial support. They are living with the hope for Anusha to recover after the operation by which she could live independently and get married.

Case 3: (Tarun 25 years old)

Tarun is a 25-year-old young man with severe locomotor impairment with stunted legs and hands. Tarun is a very bright student with 98 percent in his plus two and with a distinction in his graduation in economics honors. He belongs to the Brahmin community residing in Hyderabad. He is currently pursuing his Master's in Economics from Bhadruka College of Commerce and Arts. He comes from a family where his parents were highly educated and economically well-to-do. His father is an engineer in the Central Public Works Department (CPWD), Ministry of Housing and Urban Affairs, Government of India, and his mother is a

postgraduate (M.Ed.) and teaches in an international school. Tarun's total parental income is approximately 24 lakhs per annum. He is the second son of his family. His brother passed out from IIM Bangalore and is currently working as an investment banker in London, U.K. He was fortunate enough to have such parents who were not only loving and caring but also had a progressive and modern outlook towards life. His parents wanted to give him the best in all aspects.

When Tarun was born, the doctors did not know whether his disability was the result of an early medication that his mother had taken while the child was still in the mother's womb. His mother reflects, "he was a very healthy, normal and beautiful baby boy otherwise. I was surprised to see his legs. They were strangely twisted and born with the deformed hip joints. We thought that he would recover soon after surgery. Our first round of visit to the doctors started when he was born. Then Doctors suggested us to take him to IMS. Doctors at IMS told us that surgery cannot be done at this tender age; He can improve his functionalities with the help of physiotherapy treatment. We started giving him physio treatment when he was three months old and continued till, he was six years old. During my son's childhood days, we used to follow the physiotherapist's diet strictly. Though we belong to a vegetarian family, I have learned cooking non-vegetarian food meant to strengthen the bones. I used to give him boiled eggs and *paya* soup (soup prepared from lamb legs) regularly and continued till he was sixteen years old. Due to physiotherapy sessions his bone strength has improved and pseudo hip joints have formed. However, his gait pattern is different from others. We consulted the doctor again at the age of six, who advised us to continue physiotherapy treatment. The doctors also suggested us that corrective surgery cannot be done as it might make him wheelchair-bound. We continued his physiotherapy treatment until he was sixteen years old. We have hidden the truth about the dangers of corrective surgery from him. At the age of 23 years, he approached us saying that he wanted to go for corrective surgery. He was very angry with us for not taking him to the doctor to discuss about corrective surgery and upon his insistence we took him to the doctor. We took him to IMS once again, because we knew doctors there to whom we showed all the previous reports of our son. The doctor advised a fresh X-ray and explained everything to our son by comparing previous reports on why corrective surgery cannot be done to him. Finally, our son was convinced. The doctor recommended him to wear specially designed shoes to improve his comfort level in walking.

Tarun expresses his deep sense of gratitude to both parents for struggling so hard in his childhood days and making him independent enough to perform his daily tasks, including car

driving. He aspires to do his Doctorate of Philosophy in Economics and Finance from the London School of Economics, U.K., and thereafter get into the teaching profession in one of the reputed Universities in India. After earning some fame in society, he even wishes to marry and settle down with an understanding partner.

Tarun says, *I was very much hurt by my friends' words and wanted to go for corrective surgery. My friends humiliated me that no girl will ever wish to marry me as I look different. After listening to the doctors' words, I realized that being an educated person, I have to contribute to society by achieving something great as a responsible citizen and not worrying about small things like marriage.*

Tarun further says that the doctor has suggested him to use specially designed shoes to improve his comfort level while walking. *When I use that particular shoe, my foot rests comfortably in that cushioned sole. The appearance of the shoe is a little odd. When I use them, people pass negative comments that I can't walk without those shoes. Before using those shoes, my friends humiliated me based on my gait like, I swing like a duck and on. After started using this shoe I've become a joker in front of them. However, my parents are with me*. Hence, he realized that he would not allow people to label him and refuses to allow societal forces to 'disable' him.

Despite having multiple identities for Tarun, such as he is son of an engineer, son of the headmistress, graduated with economics honors with distinction and on, but Tarun's peers constantly reminded Tarun's' disabled identity which made him to go for corrective surgery. As he belongs to an educated family, his parents wanted him to grow up like any other normal child. He also said one good thing about his family that he was never discriminated against at his home including his close kin.

Case 4: Niharika, 10 years old

Niharika is a 10-year-old girl from Warangal suffering from 'knock knees' and currently undergoing treatment at IMS. She is the second child to her parents. She is studying fifth standard, and she has an elder brother who is in eighth standard. Her father is a Mathematics teacher in a government school and her mother is a homemaker. Her parental income is around three lakhs per annum. She belongs to the scheduled tribe community.

Her father, being a mathematics teacher, has a very good demand for tutorials. He also takes private tutorials at his home after his school hours. Both her mother and father have very good knowledge about the value of education. They wanted to give their children the best in terms

of education. They know the value of good communication skills for getting desired jobs. They have joined both their children into a Christian missionary school to get a good command of the English language. Niharika likes painting. Whenever she gets time, she always thinks about sketching something or the other. Niharika recollects, *I love painting; whenever I paint, my parents think that I'm wasting time unnecessarily. I always tell them that it is my hobby. Despite that, they don't encourage me to paint, they are least bothered to know about my interests. They believe that pursuing higher studies like becoming an engineer or doctor is the best career option*.

Niharika's Mother says that, "I always had a desire to get a girl child, I was very happy to see her in my hands when I gave birth to her. At the age of two years, we could notice that she had some trouble walking. We took her to the private ortho surgeon in Warangal. He referred us to the IMS. When we came here the doctor told us that due to vitamin D deficiency this problem arises. Then they put a slab (plaster of Paris) on both her legs. They covered her leg under plaster from hip to ankle to correct the posture of the knee. They put it for two months. After two months when they took out the cast doctors couldn't notice much difference. Then after three months, they put it for another two months and like this they continued for one year. After one year, they could notice her walking a little distance. We were happy to see her walking. At the age of five years, her gait has changed again so we bought her to IMS. Doctors suggested her to use knee braces on both legs. Doctors told us to keep it on all the time and to remove only during morning time when she freshens herself. Whenever we used to put her leg into the brace, she used to make a lot of noise which compelled us to remove that. Per day, if she used to keep it for two hours it is more than enough. She used to give reasons that she is very uncomfortable with that device. When we took this complaint to the doctor, the doctor told them that she has to wear this device so that slowly her knee posture will get corrected and she can improve her gait. She is too young to understand the things we try to explain to her and we ask her to use the device. Then Niharika straight away shouted at the doctor "*meeku cheppadanki easy ga untundi, meeru veskoni choodandi, adi enta baravu ga untundo enta noppi vastundo, inka enta doorda pedtundo two hours ki na paristhithi, idi inka roju motam naa valla kaadu, Meeru andaru okasaari veskoni choodandi na baada telustundi*." This means… 'suggesting someone is very easy, but it is very difficult to wear that, you all don't know about the trouble that I am facing whenever I use that device, it is very painful, irritable and quite uncomfortable due to its heavy weight. You all should wear this device and then you will come to know how much pain I am tolerating'. Doctors tried to convince her and explained

to her that if she won't wear it then she has to face an even tougher situation. She didn't listen at all. Then the doctor threatened saying that if she doesn't wear then she will have to undergo surgery followed by physiotherapy which will be very painful. They said to her that every day she will have to take so many injections and on…. Then she tried to wear that for six hours as she couldn't wear beyond six hours. Doctors asked us to use this device for three to four years continuously until the knee posture becomes better. Then we approached the doctor when she was nine years old. Her knee posture was worsening as she is not using the device as per the doctors' suggestion. Doctors advised her to go for corrective surgery to the knee called "corrective of osteotomy."

Niharika says that *kaallaki veskodaanki enti, choodadaaniki kooda baagodu, nannu eppatikee janmalo nadvalevu antaru, avi andari mundu veskoni tirugute inka nannu edipistaaru. Nenu edo oka laga nadichinaa janaalu ki problem. Anduke nenu naa school hours tarvata intlo ne veskodaanki isthapadtaanu.* This means… 'the device is not only uncomfortable to wear it but also it doesn't look good, people always comment me that I can't walk at all though I walk slowly with whatever gait I have… if I walk with the help of a device, people will tease me even more. That's the reason I always prefer to wear it inside my home after school hours rather than wearing it outside my home."

Niharika thinks about a different career option rather than becoming an engineer or doctor. She is too young to understand things and hasn't developed serious ambition in her life yet. Her mother recollects that, *we have to do something better for her before her marriage. Let's see what happens after the corrective surgery*.

Niharika describes her difficulty in using assistive technology. Though the use of assistive technology has its advantages, it has its disadvantages too, when it is used by the person. It is clear from her narrative that no one wants to understand the difficulties while using them. Not even doctors try to examine it because it is not their duty to bother about it, they just recommend the devices. Parents do not understand, physiotherapists won't mind and the orthotics at IMS do not bother about these issues. They are not involved in the Research and Development team. They just depend on government protocols.

Case 5: Pravallika (18 years old)

Pravallika is an 18-year-old amputee (left leg) girl. She is from Karimnagar. She is the third child and only daughter to her parents. She has two elder brothers. She belongs to a poor and

uneducated family. Her total parental income is around seventy-five thousand rupees per annum. She belongs to the scheduled caste. At the age of eighteen years, she met with one of the deepest tragedies in her life. She met with a terrible accident when she was returning home after giving her plus two exams. She was sitting in a mini-taxi which was overcrowded with eleven people when another mini-taxi hit the vehicle in which she was traveling. Due to the strong collision, she fell down from the taxi and a car passing through the intersection point passed over her leg.

Her leg was operated on and doctors tried their best to bring life to the leg but the leg couldn't survive. Doctors amputated her lower limb to below the knee to prevent further infections. Pravallika always dreamt of a beautiful life, about becoming a teacher and having a good married life. After her accident she was hopeless about her dreams and future. Now she only thinks about her independent life in terms of walking and doing daily tasks regularly that she used to do earlier.

Pravallika recollects that, *doctors could easily say that I can walk with the help of an artificial limb and can lead an independent life. No one notices the trauma of using a prosthetic limb by a new user like me. It looks strange to walk with an artificial leg. Though prosthetic limb liberates mobility, and provides independent life; using a prosthetic leg during the initial phase is very difficult. It takes a lot of time to use the leg, I mean to say that I myself have to train the leg how to walk, how to climb the steps, how to bend the knee and so on... since we belong to a poor family, proper training is not given by doctors or physiotherapists or orthotics at IMS. Physiotherapy is expensive. We are not in a position to afford three hundred to five hundred rupees fee per visit. If we visit a physiotherapist at IMS, they charge fifty rupees but hardly take the session for half an hour. Going all the way to IMS itself is a problem. As I can't go out using the public transport, I have to use private transport which is even more expensive and cannot be afforded. Doctors simply say that it's not our duty to teach me how to walk; orthotists only correct the functionalities of the prosthetic device*.

When Pravallika met with the accident her relatives criticized her a lot about the prospects of her marriage. She recollects, *my parents wanted me to drop out from my studies after my tenth and they wanted me to look after household chores. I wanted to pursue my graduation and wanted to become a teacher. My brothers helped me to convince my parents for my higher studies. In our kin group, I'm the first woman who studied till twelfth. Our family doesn't know anything about education. My family believes that a woman has to look after the household*

chores and a man has to look after outside affairs. My elder brother studied till tenth standard and is working in paddy fields with my father to help our family economically. My younger brother is pursuing graduation. Both my brothers wanted me to go for higher studies. They believe that I'm good at my studies. I always took my teacher as a role model and a source of inspiration. I always wanted to be like my teacher who can help thousands of people to know the value of education. All my efforts are in vain to become a knowledgeable person. Now all my family members, including my parents, are scolding me for not listening to their words. They are criticizing me that no person will ever come to marry me, I've to be a spinster throughout my life.

It is clear that as Pravallika's parents belong to rural area, their arguments are more oriented towards getting her daughter married to a person who will take care of her rather than giving her a good education and leading an independent life. She further highlights the problems in training her leg without the help of doctors and physiotherapists sessions. As she cannot afford the help, she has to learn everything by herself which is even more difficult.

Case 6: (Pranay 28 years old)

Pranay is a 28-year-old man who completed his B.Tech. in Computer Science from a private engineering college in Hyderabad. He belongs to Brahmin caste. He met with an accident while traveling on a train. He was traveling to Vishakhapatnam in a general compartment during the festive season of '*Sankranthi'* popularly known as Pongal. Due to the high demand in this season, he couldn't get a reservation, yet he decided to travel, which changed his destiny for a lifetime. He recollects that, "I don't know how the tragedy has happened to me, I was standing near the door, a train from the opposite direction came, due to heavy force I fell down on the tracks that's what I remembered. Next day morning I could see myself at the King George Hospital, Vishakhapatnam, with one amputated leg and the other leg with multiple fractures. Later on, I was shifted to IMS. Here, Doctors have operated on my other leg. It took more than one and a half years to recover from that tragedy. I've tuned myself both psychologically and physically to be strong to face society without a limb. During my childhood days, I was not a studious student, I was not good at any of the subjects, I just spent time like that without any reason. My father belongs to class four central government employee in the Income-tax department and my mother is a homemaker. I was the eldest son of my parents. On the other hand, my younger brother is a very studious person since childhood. He was a topper in his class, he could secure a rank in IIT Delhi. My father always used to compare me with my

younger brother and often he used to scold me like "*enduku paniki raavu ra vedhava*" which meant that I was a 'useless fellow, good for nothing.' At times I feel that God has fulfilled the wish of my father, now that I'm completely useless without a limb. Initially, when I came to know that one of my legs was amputated, it was a great shock to me. I was crushed…. Perhaps that's the first time in my life I really cried a lot. I failed in my life several times in front of my parents and my teachers, not at all doing well in my academics. I used to get bad scolding from both my teachers and parents that didn't make me cry. My father with all his hard-earned money has spent a lot on our education; I've never utilized it properly. There is a saying 'bad is always attractive.' Likewise, even I was a victim of that; I've cultivated bad habits like smoking and drinking. During my engineering days, I spent all four years with backlogs, simply smoking and drinking with so-called friends, in friends' rooms in the name of combined studies. The irony is none of my friends have visited me when I was bedridden. At that time, I came to know about the true people around me. I could understand the true social relations of family and extended family. In modern days, these relations are weakening; the majority of the youth are neglecting their families and spending more time with friends. In order to understand a true relation, one needs to have an experience like me. I'm not saying that all of your friends are always bad friends; it depends upon how you will choose. Try to choose wisely. I was fortunate enough that my parents and grandparents have supported me to the largest extent during my hard times. I remember both my mother and my grandmother have sold their gold ornaments for my treatment. I had not realized the value of purposeful and meaningful life until I met with that accident. When I was feeling depressed, my younger brother sent me inspirational videos of many disabled people who were doing wonders and were breaking the records. There is one such video of 'Arunima Sinha' which inspired me to think about disabled sports. Arunima Sinha's story is somewhat similar to mine. Being an Indian I know the plight of Indian women in general and disabled women in particular. She confronted several odds in her life and could become a mountaineer. Hats off to that great lady. This made me think about life in a different way. Now I want to achieve something in my life. I want to participate in sports. I want to become a Paralympic athlete and want to win a gold medal for India."

Pranay, in search of a meaningful life, wanted to improve his identity by training his prosthetic limb like an athlete. Pranay describes his prosthesis experience as; "initially you have to start adjusting to the prostheses by wearing it for half an hour daily. Then you start going for very short walks. He further states that you must trust your body; you must trust the leg so that you can stand on it and walk. You can't depend on crutches or a wheelchair in the long run. I have

to train my leg not only to walk but also to run. When I learn running, I will use a different version of prosthesis – I have to modify my prosthesis by attaching an electric motor (electric chip) which helps me a lot in running. I heard that this version of the prosthesis is a little expensive and is available at the different private orthotics and prosthetic centers such as otto bock, endolite, etc. IMS people referred me to orthofit to fulfill all my dreams. I also have to search for a source of funding for my training as my father cannot afford it. I guess in India we have a very limited scope for sports in general, so then what about disabled sports? It is my interest. I will search on my own for the opportunities."

Pranay's accident brought a positive change to his life. His motivation to become a sportsperson is really inspiring which might lead to mainstream disability sports. It is pretty clear that when one has a serious goal, the person is ready to fight the battle irrespective of several odds. It would be better to have one disabled sports center, so that would be an interesting development from the state for the welfare of the disabled.

Case 7: (Akhila, 15 years old)

Akhila is a fifteen-year-old girl from Warangal, born with multiple disorders like a hunch back, and improper nerve function in her pelvis that restricted her movement in walking (a type of Paraplegia), a hole in the heart, and small lungs due to which she had a severe breathing problem. She is wheelchair-bound. She is the second child to her mother. Akhila's parental income is approximately four and a half lakh rupees per annum. She belongs to Mudiraj community, an OBC caste. Her mother faced lot of challenges in her life as she gave birth to two disabled daughters. Her elder daughter was born totally blind and died at the age of one year.

Her mother said that one midnight she heard the baby crying due to high temperature, suffering from motions and vomiting. However, her mother-in–law didn't allow her to go to the hospital. Her mother-in-law didn't want to give treatment to her disabled granddaughter. She recollects, that her mother–in–law saying 'guddipilla unte enta pote enta' which means, 'what is the use of a blind child whether she is alive or dead'. The next day her baby died due to lack of medical attention in an emergency. Two years later, Akhila was born, but with a congenital disability. Due to this Akhila's paternal grandparents and her father left her in the hospital and asked her mother to leave the child and come with them. Her mother refused to go with them. Akhila's mother then took the child with her and she was brought up under the guidance of her parents. Akhila's mother doesn't want to burden her parents with two additional members for a lifetime.

Akhila's mother completed her graduation, did her B.Ed., and got recruited in a government school as a teacher. Later on, she completed her M.Ed. and currently, she is working as a headmistress in a government school in Warangal.

Akhila's mother recollects, "when Akhila was born doctors told me that she will not survive more than a year. My husband left me at the hospital as I had given birth to two disabled daughters. My in-laws blamed me for giving birth to disabled daughters. At times, I used to wonder why my in-laws are blaming me all the time, don't they think that even his son is also equally responsible for giving birth to the disabled daughters. The probable reason for giving birth to disabled daughters is consanguineous marriage. They don't accept their mistake. The irony is that my aunt wanted me as a daughter–in–law to his son before my marriage but after giving birth to two disabled daughters' my aunt doesn't want to accept me as her daughter-in-law. My mother-in-law wanted to have a second marriage for her son. I left that home, their memories, and everyone at their place, happily signed on the divorce papers and came to my natal home. I've seen Akhila as a ray of hope when no one is with me. At that point, I've decided that I will put all my efforts to raise this child. Though doctors said that she won't survive more than one year, I didn't believe at all. Now, she turned fifteen years. I used to believe that miracles do happen. I thought sincere efforts, with little treatment, wholehearted prayers of everyone at my natal place have really worked for Akhila. Especially in her case, everything took a little extra time. She also had delayed puberty. Though, I accept the fact that currently she has difficulty in walking, I believe that one day she will overcome it. I also dreamt of Akhila having a very bright future. One day, she will walk, dance, and settle down in a good position and make me feel proud. At that moment, I will introduce Akhila to her father and paternal grandparents and want to say that I'm not the sole responsible person for giving birth to a disabled child but I'm the sole responsible person for bringing up the disabled child." Akhila's mother describes her marriage as a tragedy and she says that she doesn't want to repeat that tragedy in Akhila's life.

Akhila underwent a total of four surgeries so far to improve the quality of life in all aspects. She underwent heart surgery; she corrected her spine to improve the posture of the spine and her pelvic region. She improved her breathing capacity. Akhila recollects that, "doctors told me that after surgery my pelvic region has restored its functioning. Maybe one more surgery and after doing sincere physiotherapy for a few more months might improve me in walking. I'm confident enough that one day I will walk because now doctors are giving assurance. During my childhood days doctors didn't give me any assurance for my survival but somehow,

I managed to survive; now doctors are giving me assurance about my walking. By hearing this news, I am very happy, no bounds to my happiness at all because as a wheelchair user I had very bitter experiences. It is one of the greatest achievements of my life. I feel as if I'm going to win a gold medal in the Olympics."

When the researcher further enquired what enjoyment means for her, she said that enjoyment means to walk and go wherever she wants. She doesn't like to depend on others for everything. Hers is a manual wheelchair. The researcher asked her, "what if you have a powered wheelchair? Do you still feel the necessity to walk?"

Akhila laughed and said, "wow! There are powered wheelchairs. I didn't know about it. Of course, there is the necessity to walk, no matter, even I walk with support, for every small distance you notice, my grandfather lifts me up and again keeps me on the wheelchair whenever necessary. I feel, even a powered wheelchair can't help me on the steps, I've to walk as I grow up. I put on weight and I don't want to burden my family with my weight. It's not about what others think about me when I use a wheelchair, it is about the conditions in India especially in rural areas like Warangal where you can't use a wheelchair because the roads are not disabled-friendly."

It is pretty clear that Akhila's mother wanted her child to stand on her own in terms of education and employment rather than getting her married to somebody. She always wanted her daughter to be strong and she is making her daughter fight against several odds in the society. On the other hand, Akhila highlights the problems of a wheelchair user, public transport, and environment, etc.

Case 8: (Padma, 20 years old)

Padma is a 20-year-old amputee girl from Khammam. She is currently pursuing her graduation in Commerce. She is the eldest daughter of her parents. She has one younger sister. She belongs to Vieshya community. Padma and her parents didn't reveal their annual income. They said that, "since we belong to the Vieshya community we depend largely on business; we can't say how much income we will get per month or annum." Her accident was unexpected, unbelievable and the greatest tragedy that ever happened to her family.

She describes her tragedy as, "while I was studying my plus two, a thumma mullu (thorn of a tree *Prosopis juliflora*) got accidentally pierced into my right foot. I removed it with the help of a safety pin and it bled. I went to a local doctor and he did dressing, and put a band-aid on

it. I thought it came out. After two years, a crack was developed and pus was oozing out of the wound. Again, I went to the doctor. He gave me some antibiotics and again the wound got healed. I could find the wound every two years and it used to disappear after using antibiotics for three months. When I turned eighteen, this time the wound didn't heal, antibiotics didn't help me. I was also attacked by diabetes as a result of hereditary disease; that's the reason the wound didn't heal properly. I was asked to shift to the IMS orthopedic department by the doctors in Khammam. I was shifted to the IMS, expecting that I will find a permanent solution to my feet but I was named as permanently disabled at IMS. At IMS, doctors diagnosed that the infection had spread to my knee, so at IMS doctors amputated my right leg below the knee. I was frightened to see my leg. I can't stand, can't walk. I underwent a great psychological trauma.

When one undergoes the training phase of a prosthesis it is like 'how the hell am I going to train with a single leg?' Before I lost my leg, I could easily stand on one leg. But, now… I can't even stand; I can't keep my balance on one leg. However difficult it is, life has to go on… It is my goal to get back to work again. It may not be realistic, but one needs to have a goal… if you don't have goals, you might as well give up."

Padma says, "at times depending on the day, wearing prosthetic legs can be frustrating and sometimes humorous. I remember when I used it for the first time, it was the most uncomfortable, unrealistic, crappy stilts I've ever worn. I hated them and often refused to wear them. I preferred to walk on my knees or use a wheelchair. I don't know about different versions of the prosthesis. The only thing which I am familiar with is the Prosthesis given by IMS-ALMU. I trained my body to use a leg when no other option (I cannot afford prosthesis provided by the other private organization) is available to me. While in hospital I found no emotional support at all. They give you no information on the procedure, the way it will affect your life, and how to cope with it. One thing I have noticed is; you have to be very strong when no one supports you. Although high-tech prostheses are available, nothing can replace an original leg when compared to an artificial limb. Today the extensive use of prosthetic legs has resulted in lumbar complications and residual stump issues. While the use of prosthetic legs provides increased mobility and independence, it also has its own disadvantages. Long term use puts a toll on the rest of the body, primarily the back. As long as our body cooperates, we have to see the positive corner of a prosthetic limb."

Padma in her narrative describes the disadvantages of using a prosthetic limb in the long run which might further lead to several other complications resulting in the damage to the spine. She also describes how her home became difficult in accessing the spaces around the home which earlier she used to navigate effortlessly. Life after amputation is not that easy to deal with. Forget about higher ambitions, her everyday life has changed completely after the surgery.

Case 9: (Anil, 6 years old)

Anil is a 6-year-old boy from Karimnagar. He was born with distorted limbs and was referred to the IMS hospital in Hyderabad city. He was diagnosed with Paraplegia and labeled as permanently disabled by the doctors of IMS. Anil belongs to a lower-middle-class Christian family. His family income is less than one lakh rupees per annum. Both his mother and father work in a clothes shop. Both of them are not educated. He is the second child. His parents wanted to see their son well educated and to see him in a good position. They feel that unfortunately, *devudu ki memu ante kopam emo, anduke memu sukham ga undadam deveudu ki istham ledu, anduke maaku ilaanti bidda ni ichaadu* which means that 'God is angry with us and maybe he doesn't want us to live happily, that's the reason why he has given this type of son to us.'

Anil is studying in a private school near to home. It is becoming difficult for Anil's parents to take him to the school by carrying him all the way to the school. Again, they approached the IMS doctors to do something to improve his functionality. Doctors told them that even if Anil undergoes surgery, it will be in vain. Doctors referred him to the IMS-ALMU for a wheelchair or tricycle. Anil's parents took him to the unit. That orthotist asked them for the disabled certificate. Anil's parents didn't know about disability certificates, or where to get one. Orthotist told them to go to the doctor and ask them about a disability certificate. Doctors ask them to come either on Monday or Wednesday to give the disability certificate. On further inquiry, doctors told them that a disability certificate can be given during medical camps organized by the hospital. They came on Monday, took the disability certificate, and went to the IMS–ALMU Unit. There they asked for several other certificates like income certificates, Aadhar card, and on. They did not know whom to approach for all of this paperwork.

Anil's father discussed the burden of getting a few orthotic devices as it includes several procedures in getting a free device. Being an uneducated parent, he was not aware of these certificates, pensions, and on. There should be some public programs to bring awareness among

people about how to get the certificates, whether it could be a disability certificate or income certificate or aadhar. They suggest that there could be volunteers who can guide them in getting these certificates. On the other hand, people should empathize and positively respond to them and try to give the products as early as they could. Since it is a problem to travel all the way from their native place to cities, if these government ALMU centers are set up in all the district headquarters if would help poor in a big way.

Case 10: (Bhargavi, eighteen years old)

Bhargavi is an 18-year-old girl from Hyderabad. She is the eldest daughter in the house. She has two younger sisters and a younger brother. Her father is a clerk in a government educational institution and her mother works as a daily wage laborer in a printing press near to their home. Her parental income is approximately around four lakhs rupees per annum. Her father studied till twelfth and her mother doesn't have any formal education. She belongs to a Kummara community, an OBC caste. Bhargavi is suffering from cerebral palsy.

Bhargavi's birth is considered to be worthless; her father doesn't want to take her for any further treatment. He opines that it is unnecessary to spend money on her treatment. In fact, he wanted to throw the child out, but her mother requested him to keep the child as long as she lives. Indeed, Bhargavi's mother, after giving birth to Bhargavi, couldn't conceive for four years. Her father wanted to divorce her mother at that time. Bhargavi's maternal grandmother came and requested her son-in-law not to leave her daughter. For that she gave an extra plot of hundred square yards in Janagam as a token of a gift for keeping her daughter with him. After that, they went and used a lot of medicines for conceiving. She gave birth to a healthy son and later on two healthy daughters. Other than Bhargavi, all these three were nicely taken care of by their father in terms of their education, their favorite food, etc.

After giving birth to Bhargavi, they didn't take her to the hospital at all. According to her mother, had they taken her to the hospital during her childhood, her impairment could have been reduced. On further inquiry, her mother says that now the reason for taking Bhargavi to the IMS for a regular checkup is to apply for a disability pension. She further recollects that, *my husband came to know that the Telangana government is giving disability pension on time. He thought of getting that money, he manipulated his income certificate, in front of the doctors he pretended as if he loves his daughter, he got a disability certificate for her. He manipulated and got a wheelchair for her. He said to the doctors and orthotics that he will provide good education for his daughter.* Her mother says that the wheelchair given by the IMS-ALMU is

also lying at one corner of our house like Bhargavi. She says *Bhargavi would be there as long as I live.*

Bhargavi doesn't have an aadhar card to get a disability pension. Her father tried all his best to get an aadhar card but couldn't get as her fingerprints are not recorded properly. All her father's efforts are in vain to get a disability pension. Her father is disinterested with her future.

From the above, the notion of being disabled as 'too unfit for living a good, energetic healthy life' has deeply rooted in Bhargavi's father. It is very strange to know that a parent is not able to accept a disabled child. When their parents are discriminating against their child then what might others think about disabled children? Bhargavi doesn't even get the right food and due to lack of nutritional food her fingerprints were not noticed in biometrics in the aadhar department. Her father doesn't have minimum human values; on top of it, he wanted his daughter's pension. His patriarchal mindset seems to be not changed.

Case 11: (Pratyusha, 25 years old)

Pratyusha is a 25-year-old girl from Secunderabad, Hyderabad. She is currently pursuing her Masters in Psychology from Osmania University. She is the eldest daughter to her parents. Her mother is a homemaker and also runs saree business at her home during her free hours and her father has a grocery shop. Her parental income is around five to six lakhs rupees per annum. During the festive season their businesses make good profits. She belongs to Kamma community.

According to Pratyusha, her accident was an unforgettable event in her life. She was learning karate (a form of martial arts) and she used to go for classes early in the morning daily. One day, around five in the morning, when she was going out on a scooter, she hit the divider forcefully and she fell in the opposite direction. Her skin around her leg was damaged to the extent that she could see the bone. In an emergency, she was taken to Gandhi hospital and from there she was referred to the IMS ortho department. Initially, doctors told them that they can't go for the surgery. First, they started her treatment by dressing the wound. Doctors told her that first, the wound around the skin has to heal after which they might go for further treatment. Fortunately, there were no fractures in the bone. The ortho doctors tried their best to heal wound. Since the wound was not healing properly, they referred her to the plastic surgery department. At the plastic surgery department, they operated on her thrice to heal the wound.

However, after several attempts at healing the wound failed and the leg developed complications which led to the amputation of the leg.

She recollects that, “instead of healing the wound, I had to take the decision of saving my life by losing a limb. In the last surgery, I was not scared of the surgery, because I already underwent two surgeries. I was worried about my future. I didn’t know what would happen to me. I didn’t want to think about it because there were too many uncertainties in the future. I asked my doctor to perform an amputation. I wanted to get relief from my suffering. I knew I could wear a prosthesis after amputation, but I was not sure how many functions I could perform. I wanted to end my suffering right away. On the other side, I was afraid that more suffering would come after amputation, both physically and psychologically. After amputation, I couldn’t believe it happened. I cried all the time. I couldn’t stop my tears. I was very angry and hated myself, I was even afraid of looking at myself into the mirror… Many times, I felt that I should have changed the doctor or shifted to the other hospital right away when he couldn’t handle my wound. I felt that I’d taken the wrong decision of losing a limb.”

After amputation, Pratyusha was depressed most of the time and she expresses her loss of a limb as, “since the day I lost my leg, my nightmare began. My leg was one part of my body. It had vitality. When I thought about the leg I lost, my heart was broken. The pain was endless. I couldn’t imagine feeling normal again…. Though I’m from psychology, I need to tune my brain psychologically…. I was exhausted and used to tell my family members … you people don’t understand how much I suffered every day. Only people who have experienced would understand how painful this is. At the same time, I felt so sorry for my family, I was unable to complete anything by myself. I wanted to be independent, but I couldn’t. Moreover, the worst and the most frightening part was to deal with the significant others or so-called relatives… I am worried about other people’s judgment. I didn’t like it when people paid attention to my leg. It was so embarrassing for me to show my stump to others. I knew most of them might not accept my appearance after amputation…. I’m least worried about my marriage and I don’t like others discussing this subject. For an amputee, the main objective would be how to rebuild confidence in oneself rather than marrying and depending on others… I still couldn’t accept my loss, but I tried to change my view on life. Some are good days and some are bad days. Finally, I realized that the bad days were not so bad. Everything I had to do could be done in a different way now. Life was not going to change for me – I needed to change myself. Initially, I believed that I was the worst one. Then I saw people at the IMS-ALMU who were worse than me, such as those with bilateral amputations (the surgical removal of more than one limb, either

both lower extremity or upper extremity) … there were older people than me, struggling to walk with heavy legs. I took inspiration from them. I started believing in myself… I haven't walked for a few years since the surgery. For most people walking is a natural and very simple phenomenon. But to me, it was so difficult. When I took my first step, I cried out of happiness and felt so happy, I could walk again. My life was back… one thing I was more conscious of was about the appearance of a prosthesis. Even aesthetically, as a woman, I want to make sure that the prosthesis looks good, especially if I'm wearing a dress. On the further recommendation of IMS-ALMU people, I went to Orthofit to get the advanced model of lightweight Prosthesis. I cannot complain about anything. When I was in the hospital, I had a good support from the doctors and nurses to change my dressings, and the physios have trained me to walk… They were all supportive and were there to help me whenever there is a need. Though, I went to Orthofit to get the prosthesis I'm connected to the ortho doctors of IMS and IMS-ALMU. One thing which I noticed in a private clinic is the availability various designs and models of prosthesis depending on the affordability. Aesthetically you will notice different versions of prosthesis that match your body color. I feel that since it is based on German technology, it is designed to suit the needs of the western people. The material in the socket which is used to attach to the stump is made to sustain a cold climate. Our climate and geographical conditions are different from other countries… During sunny days, I feel that though I can walk easily, due to heat, I could develop rashes and sweat all over my stump. During sunny days, I prefer to sit at home rather than going out with my prosthesis."

Case 12: (Veerababu, 35 years old)

Veerababu is a thirty-five-year-old man from Nellore, currently working in a printing press as a supervisor. His income is approximately around two and a half lakhs rupees per annum including incentives. He has dropped out from graduation due to financial constraints in his family and his wife studied till tenth class. His wife is a homemaker. He has three children; one daughter, and two sons. His daughter is in the playschool and his eldest son is studying in third class and his youngest son in first class. He belongs to the Schedule Caste community.

His accident can be described as the result of sheer negligence in one's life. A case of drinking and driving. It was around 10 PM that night when Veerababu and his friend went to a party from the workplace. They were fully drunk and were riding a bike. Veerababu's friend was driving and Veerababu was the pillion rider. Veerababu's friend hit the divider and both fell, A lorry coming from the opposite direction passed through Veerababu's left leg. His leg

suffered multiple fractures. Both of them were unconscious as they drank heavily, were taken to the nearby hospital for the first aid. Later on, Veerababu was shifted to IMS hospital. As Veerababu was unconscious, doctors decided to amputate his leg to save his life.

Veerababu describes his experience as, "when I opened my eyes… I noticed something is missing in my body… I couldn't get up from the bed and the reason is I could see only a shorter leg (stump). I was in constant pain, I was afraid of my future, I started thinking about what happens to my wife and children. The pain is more intense when I think about my family … It was like a nightmare. By the time I realized that I'd committed one of the biggest mistakes, nothing was in my hands. I have stayed at home for a year and it made me feel inferior because I could no longer be my family's breadwinner. This made me think twice or thrice before I meet someone. I was worried about reactions from the others. I didn't want my relatives to meet me. I didn't want my friends to visit me. I didn't want them to pity me or feel sorry for me. I knew people passed negative comments at the back of me like I'm such an irresponsible husband and father and on. I knew very well that I've committed a mistake. It is very hurting when people come and pinpoint my mistake in front of my children. The best way to avoid this was to isolate myself from the others. Initially, after amputation, I thought my life was all destroyed. I lost my temper easily, I looked at the dark side of everything. But I gradually found that my pain was worse; I couldn't sleep and eat well. My children were scared of visiting me and they visited me less and less…. It is very difficult to manage things after amputation. Initially, you have to depend on several members to do small things. My home has become a new place for me. One day, I fell in the bathroom, I told my wife I didn't want to live anymore. My wife told me, 'If you die, I would also die with you.' She couldn't live without me. She also asked me to think about my three beautiful children. My wife never wanted me to take a motorcycle for fear of an accident. I felt my family including my wife needed me and it was my responsibility to take care of them. Since that day, I never said I wanted to give up. I must live for my family members… After making up my mind I started walking with my prosthesis within three months. I'm not bothered about the quality of the prosthesis. While I was bedridden, the amount of mental pain that I underwent didn't allow me to think about the quality of the prosthesis. I am walking again and things are coming back to normalcy…. I felt my family as a ray of hope"

Societal attitudes made Veerababu think that he is isolated and a burden on the people in his life. He couldn't even find a single reason to lead the life he was compelled to, thinking that he cannot perform any social roles, like, being a father or being a husband and on. He felt that he

wanted to give up his life for the mistake he had committed. He hated how painful it was when his children were scared to see him. The social status of the man being a breadwinner of the house felt lost. At some point, he finally felt he was needed for the family and started to rethink his new life.

Case 13: (Saheena Kathoon, 40 years old)

Saheena Kathoon is a 40-year-old lady hailing from Mahbubnagar. She is the mother of three children. She got married at the age of sixteen. Her eldest daughter is married and has one son and another daughter. Her youngest daughter is recently married and the son is studying Intermediate in a government junior college. Her husband runs a local mechanic shop in the market. They don't have any fixed income. Her husband studied till fifth class. She recollects that, "as far as I remember I have not enrolled myself in school."

She is suffering from diabetes since the age of thirty. She developed Osteomyelitis at the age of thirty-six, and had to undergo below-knee amputation to the right leg at the age of thirty-eight. To end the suffering, she opted to go for the surgery at IMS. She recollects, "I could fulfill all my major duties as a responsible mother. I've married off both my daughters at the right time. 'Mujhe Abhi meri zindagi ki koi Parvah nahi hein'', which means 'I'm least bothered about my life, that's the reason I've decided to lose my limb'.

"The worst part is my grandchildren are scared to visit me, they are not even allowing my children to come and see me. The only thing which worries me is… when my grandchildren visit me neither I can fetch them a glass of water nor I can play with them... This made me think about walking. Earlier I used to walk short distances easily, now I've cultivated a fear of falling down. Being an overweight person, I've fear of breaking bones again and again…"

From the above, it is clear that she was not discriminated against based on getting married to a person, unlike other teens who were going through the pain of not getting married. According to significant others, as a mother, she could fulfil all her duties on time but no one is recognizing her life and the amount of pain she is undergoing. As a human being, she has her own private space but no one is bothering to know about her interests. How difficult it must be to stay on the bed all the time? How long might her daughters cope with her is the major question that might be haunting her always.

Case 14: (Nirmala, 38 years old)

Nirmala is a 38-year-old married woman from Warangal who belongs to the Kamsaali community, an OBC caste. She didn't go to school and doesn't have any formal education. She was married at the age of thirteen. Her husband works as a daily wage laborer on a construction site. Their income is not fixed. On further inquiry, she informed that it could be less than seventy-five thousand rupees per annum. She has a daughter and a son. Both of them are married. Son studied till tenth and daughter studied till seventh class.

She recollects that, "both of them are not good at studies, hence decided to drop out of school and reduce the burden on us… They were studying in the government schools; My son started helping my husband on the construction site before his marriage". Her daughter-in-law doesn't want to be in a joint family, hence they moved to Hyderabad in search of work. Her husband is a very nice person, after work he used to straight away come home. He was a homebound person.

She used to help her husband on the construction site during their hard times. Nirmala decided that she would join the construction site as a daily wage laborer along with her husband because their daughter was coming home for a delivery which requires money for expenses on hospital and medical bills. Both of them met with an accident on the construction site. A slab fell on them. She recollects that, "in that incident, many were injured but I lost my husband and I lost my limb. Neither my daughter nor my son came and extended a helping hand to me. My daughter is scared of her in-laws and my son is scared of his wife. At that moment, I was so scared that this would mean I could have to lie in the bed for the rest of my life without anyone. I thought that if I couldn't walk by myself and have an independent life then I would prefer to die now… I keep thinking about why God has kept me alive? But I keep telling myself that God has kept me here for a purpose."

She further states her difficulties in getting her prosthetic limb at IMS- ALMU as, "I have come from Warangal, I am a below knee prosthetic user. The travel from Warangal to Hyderabad is very expensive for me. Since I cannot walk, I have to travel by auto-rickshaw. After I came here and produced the necessary documents, they took my leg measurements and asked me to come after two or three days. On the third day, these people asked me to come after ten days, since they will give these devices on the occasion of World Disabled Day, i.e., on 3rd December. How will I manage till that time, how much I have to invest in autos for my traveling? When I can't afford much, how can people expect me to come very often? These people were telling

me very proudly that I will receive this assistive device from the Minister on the occasion of World Disabled Day. Though, I tell them the fact that I am not even accompanied by my family members they respond to us the way they think."

She states that no one thinks about the financial burden which she has to undergo without any support from others. She is currently managing with some work and her son adjusts the amount whatever little he can. She is also getting the disability pension of three thousand rupees and the widow pension of thousand rupees from the Telangana government. She recollects that, "both my children are really good. We have brought them up in such a way. What will they do when my destiny is written like this…? Both my children couldn't realize the value of education until they were married and taking up family responsibilities. Because we don't have any fixed income, for every minor thing we need to calculate and move. Now both of them are realizing that, if they had studied, then they would have led their lives in a much better way. They say that family responsibility and financial burden is more difficult without education."

It may be surmised from this narrative that dealing with issues alone really needs guts and thIs woman is an example of not giving up her life that easily. She mentions the problems in getting devices and at times how difficult it might be to look after things on her own. She has everyone but was isolated from their children due to other personal reasons. Unlike western countries, where the state looks after the needs of the single disabled woman or man, in our country we don't have that option where the state could look after the needs of lonely people like Nirmala. Though there are NGOs which are standing for the need, it would be better to have state intervention so that people can have easy access to everything when emergency strikes.

Case 15: (Nisha Gopika, 23 years old)

Nisha Gopika is a 23-year-old girl from Sangareddy, a district headquarters town near Hyderabad, with a passion for music. She is also good at her studies and always gives a hundred percent to score first rank in her class. She is pursuing her B. Tech. She is the eldest daughter of her parents. She has a brother and a sister; both of them are younger to her. She is suffering from a fragile bone disorder, which means her bones tend to be very brittle and break easily.

In that process, she has had 16 fractures and underwent a total of eight surgeries to correct her bone disorder when under 12 years of age. For every limb, she has implants inside her body. Her body is fixed with several screws, nails, rods, and bolts from her spine to leg. She recollects that, "my doctor calls me an iron lady." Her father runs a cab business and completed his

graduation with a Bachelor of Arts, and her mother is a teacher in a private school who completed her graduation and B.Ed.

She describes her life as, "during my infancy, which is perhaps when I was one and a half years old, I underwent two surgeries. At that time, I have no idea what I went through. I remember when I was nineteen years old; I've witnessed the most dangerous phase in my life. I fell down from the steps in my college and I had broken all four limbs and my spine. Luckily nothing happened to my neck and nervous system. But within three years I underwent a total of six surgeries. I had a very good recollection of this trauma and surgery where you will notice several phases. I do remember… while I was being taken to the emergency room, I felt that I had entered the first phase, in which, doctors try to re-align the fractures by manipulating the bones from the outside – lots of pulling, pushing, and grinding with blinding pain. This drove me to beg the orthopedic surgeon during pre-operation to save my limbs and life. Then I entered probably the second phase, I woke up post-operation in agony, I was awake the whole night with severe pain, pain that would gradually, but very slowly weaken. The pain was my new companion for many months. So, I began my very long, frustrating recovery. I couldn't wash, I couldn't feed myself, I couldn't hold a book to read, write, etc. I was, however, able to go on through blind determination. I was not about to give up on that. I was in a really miserable state that would last a very long time. It is times like these that you learn a lot about those around you. I learned who really cared and who didn't. I had some very close friends who never even called and some distant friends who called me and visited me. It was a real eye-opener and caused me to make major changes to my friendship circles. Luckily all my family members were very supportive and especially my mother worked selflessly to help me through it, with no complaint or reward, she is an absolute blessing. I have no idea how I would have recovered if it wasn't for her…. Then comes the final phase, the months that came were very difficult, the recovery and rehabilitation were long and slow. You never know whether you would be able to walk with assistance or without assistance. I was dependent on many orthotic devices like a walker, stick, to correct my ankle deformity- ankle-foot orthosis, knee brace, and spine brace and on… during my learning phase. In this phase, I developed a generous serving of Post-Traumatic Stress Disorder (PTSD). Luckily the orthotic devices I used were temporary. I must be thankful and grateful to God. Though I limp, I'm fortunate enough to feel that I'm not dependent on any device. I don't like when people stare at me. It makes me feel weird and uncomfortable. Slowly, I have now recovered with only a little functional impairment. Four years and eight surgeries later I am back on track. My body might not be so-called perfect, but

it has recovered beautifully, thanks to the entire team of Orthopedic surgeons at IMS, as they dealt with my problems very patiently. They motivated me to walk; I could also overcome PTSD with the help of a psychiatrist."

From the above narrative, Nisha Gopika describes the traumatic experience of her pre and post surgeries. She was happy to say that all the devices which she used were temporary, which means she doesn't want to carry the stigma of using assistive technologies further in her life. Even the notion of disability being stigmatized is deeply ingrained in people's lives irrespective of their educational background. As she can afford to spend more on her treatment, she could see a more positive outcome in terms of recovery.

Conclusion

This chapter presented data from the field along the lines of analytical categories such as gender, identity, body, etc. It also presented narratives of few select cases highlighting the lived experiences of respondents. Next chapter focuses on the anecdotal and statistical evidence to the contexts established earlier in the thesis.

CHAPTER 5

Assistive Technologies: Expectations, Experiences and Challenges

This chapter presents the lived experiences of the respondents of the study i.e., orthopedically challenged who are the users of assistive technologies (abbreviated as ATD- assistive technology device). The importance of assistive technology in dealing with impairment is well known. However, negotiating any technology is socially conditioned. Hence the experiences of ATD users vary based on sociological issues like gender, caste, class, rural-urban, etc. The chapter delineates the experiences of persons using ATDs with regard to the social factors influencing access, use, quality of life, perceptions of others and negotiation with identity, stigma, independent living, etc. The study accessed respondents through state and private artificial limb manufacturing units located in Hyderabad. Personal interactions and semi-structured interviews with the ATD users in both the settings yielded data relevant for the study. The present chapter discusses the sociological issues of how data were collected from doctors, physiotherapists, and orthotists involved in providing treatment to PWDs who come for ATDs also.

The term ATDs is used referring to the assistive technology equipment available in the form of prosthetics, orthotics, etc. An orthosis is an orthopedic brace while a prosthesis is an artificial limb. The term assistive technology is a generic term which refers to products and services. The researcher uses the term Assistive Technology Devices broadly referring to ATs. This chapter largely discusses about the perceptions, and experiences of the users of ATDs in their use in terms of functionalities, perceptions of others including medical professionals, family and kin group, etc. using ATDs.

Assistive Technologies and Their Reach

Access to assistive technology, more specifically, artificial limbs and orthopedic braces is made possible by state and non-state for profit organizations in Hyderabad. However, the study was carried out in two institutions a state-run institution named, IMS-ALMU (Institute of Medical Sciences-Artificial Limb Manufacturing Unit) and Orthofit, a private for-profit organization.

Institute of Medical Sciences-Artificial Limb Manufacturing Unit (IMS-ALMU) is a state funded organization in Hyderabad specializing in orthopedic treatment. The Artificial Limb Manufacturing Corporation wing has been established in reputed orthopedic hospitals in all major cities in India. This corporation aims to provide support to those persons with orthopedic

disabilities who want to go for prosthetics. Under scheme 'Assistance to Disabled Persons in Purchase of Fitting Aids and Appliances (ADIP)', assistive devices are distributed at no cost for the needy whose annual income is less than one lakh rupees.

One such limb provided at IMS-ALMU is the Jaipur Foot, or Jaipur Leg, an affordable rubber-based prosthetic for those with amputations below the knee. Dr. Pramod Sethi and the craftsman Ram Chandra Sharma collaborated on the design in 1968 and it allowed many differently abled persons to walk, run, work in the fields, and even climb. Technically speaking, the Jaipur Foot is a reinterpretation of the Solid Ankle, Cushioned Heel Foot (SACH) but the redesign and implementation was masterful enough for the Jaipur Foot to be listed among the greatest inventions of the 20th century by the *Times* magazine. Named after Jaipur, India, the leg is cheap to produce, water-resistant, and durable (Bhargava, 2019).

The IMS-ALMU is government-funded while Orthofit is a for profit organization. Both the organizations cater to the needs of the orthopedically challenged persons. Although the goal of the two organizations is similar, to help enable the locomotor disabled overcoming physical limitations by providing artificial legs and orthopedic braces, the operational aspects differ quite significantly. The Orthofit is a private organization aims to generate money through the sale of prosthetics and orthotics. It has access to global level state of the art technologies in the field of prosthetics and orthotics. It offers a variety of ATDs at a cost. Both the units offer services to all the needy, however, those who can afford generally access ATDs from Orthofit because of its quick service and advanced material and technology used in the making of ATDs which is claimed to enable the users to perform their functions nearer to normalcy.

While prosthetics and orthotics are functionally similar, a prosthesis acts as a replacement for a limb or part, while an orthosis assists the existing body part. Both are externally applied assistive devices that must be worn directly on the body.

The study collected data from forty ATD users. These forty respondents are part of sixty respondents, whose details were discussed in chapter four. Out of forty respondents twenty-seven use ATD made by IMS-ALMU while the remaining thirteen use the ATD provided by Orthofit.

Table 5.1: Respondents Profile

Category	No. of respondents		
	IMS- ALMU	Orthofit	Total
ATD users	27 (67.5%)	13(32.5%)	40
Men	18 (45.0%)	9 (22.5%)	27
Women	9 (22.5%)	4 (10.0%)	13

According to the Head Orthotist of IMS-ALMU, the material used in the making of prosthesis and orthotics is important aspect in the acceptance by the orthopedically challenged users. The material's weight is the first point of disappointment as the users prefer lightweight ATDs. He says, "these days rocket waste materials are used in making all types of calipers called orthotics. Dr. APJ Abdul Kalam and his team, in particular, worked tirelessly to produce calipers that weigh nearly $1/10^{th}$ of the original weight. This breakthrough made the ATD less painful to use and it is now possible for even children using them to walk freely".

At Orthofit, according to an orthotist working there, ATDs are produced using advanced technology-based material like silicon leg, microprocessor-controlled C-leg, and powered wheel chairs to enhance functional capabilities to user. The ATDs produced at Orthofit are considerably of less weight thus gaining wider acceptance among the users. Apart from this, device aesthetics is increasingly becoming important these days.

Table 5.2: Type of ATDs and Organization

Type of organization	Prosthetics Users	Orthotics users	Total
IMS- ALMU	12 (30.0%)	15 (37.5%)	27
Orthofit	10 (25.0%)	3 (07.5%)	13

Despite the advantages of light weight and aesthetics of devices majority of the respondents, i.e. 27 use IMS-AMLU produced ATDs. However, 13 respondents could afford the advanced ATDs produced at Orthofit which are light weight and aesthetically appealing.

Large majority of the respondents came to know about the sources of ATDs through doctors, who referred them to Hyderabad for treatment from their native towns. Only one respondent came to know through newspapers.

Table 5.3: Awareness and Type of Organization

Source of Awareness	IMS-ALMU	Orthofit
Doctors	26 (65.0%)	9 (22.5%)
Newspaper	1 (02.5%)	4 (10.0%)
Total	27	13

Issues in Accessing ATDs

It was found in the study that accessing ATDs from IMS-ALMU was difficult. IMS-ALMU being a state funded organization demands proper documents from the needy. This is because the ATDs are provided free of cost by IMS-ALMU. Maintaining records of the beneficiaries thus is an important task at this organization. Hence, the staff at IMS-ALMU demand all the required documents. This is burdensome process for the needy because those who come to IMS-ALMU are mostly poor who do not have sufficient documents. Lack of awareness about the need to carry and submit the documents also make the orthopedically challenged and their family members to make several rounds to the hospital. The documents required are disability certificate, income certificate, and Aadhar card for getting the devices free of cost from the IMS-ALMU. A respondent's father says…

my son is suffering from Congenital talipes equinovarus, also called as club foot, since his birth. He is six years old. At the age of one, he was facing difficulties in walking. We approached a doctor in Karimnagar who recommended the use of orthotics (braces/foot-ankle splints) for his both legs. We used these for two years. Later on, we didn't notice much difference in his walking. We again approached the doctor who referred us to IMS. At IMS the doctor recommended another set of orthotics called calipers which supports knee and foot and advised using it for another two years. The ALMU division at IMS were asking for disability certificate to get the calipers for free of cost. But my son doesn't have disability certificate till now. We approached the same doctor for disability certificate. But the doctor was very angry at us for asking the certificate. Along with the disability certificate at IMS-ALMU the staff are asking for my income certificate. When you visit a hospital, will anyone carry income certificate along with you? These people are asking documents as if we carry them all the time with us (father of Anil, 6 yrs old).

Another respondent who hails from Mahbubnagar, located at about 150 KM from Hyderabad, reported her experience related to documents. She says,

All the way, I came from Warangal. Doctor in Warangal referred me to IMS hospital for further treatment. I am a diabetic patient and I lost my leg due to gangrene developed in my ankle. I am a below knee prosthetic user. What I have learnt after coming here is that getting ATDs for free of cost is not an easy process. In order to get necessary ATDs we have to get income certificate, about which we don't have any idea. We don't know who gives that certificate and how to get it. Maku emi asthulu unatyi amma, poota tindi kosam kastham chesukuntunnam! (What assets do we have when we are struggling to feed ourselves for one basic meal in a day!). I came to know that I have to apply for income certificate at the municipal office and it takes about two weeks to get it. It is very difficult for me to travel all the way from Warangal to Hyderabad, as I don't have a leg. I can't travel by bus, and on top of it there should be someone to escort me. Travel all the way from Warangal to Hyderabad is very expensive for me. I have to take an auto-rickshaw to Hyderabad. After I came here and produced the necessary documents, they took my leg measurements and they told me that they have ordered my device, it takes another 10 days to get ready, so they asked me to come on the 10th day. When I came on the 10th day, the unit people asked me to come after 15 days, they told me that since they are giving this device for free of cost, they will give this device on the occasion of World Disabled Day, i.e., on 3rd December. How will I manage till that time? In the name of free of cost devices, I have spent around 3000-5000 rupees for my auto fare. Above all whenever we are traveling to Hyderabad; we are missing our days wages. When I can't afford much, how can people expect me to come very often? The ALMU staff were telling me very proudly that I will receive this assistive device from the Minister on the occasion of World Disabled Day (Nirmala, 38 yrs old).

Another respondent says that

I was given a hand rimmed propelled tricycle on the occasion of World Disabled Day. I got to know about this through one of the doctors at IMS, when I went to get my Disability Certificate. Both my legs were affected due to polio. I can't walk and I have weak muscle system. I thought this tricycle will enable me to lead an independent life. My dreams were shattered when I started using this tricycle. In our lane for every two or three furlongs there are potholes. It is very difficult for me when my tricycle gets stuck in those potholes. I have to use my whole body in order to come out of it. We don't have adjusting cushioning system, sitting on it and travelling a while is very painful. Then I came to know about powered wheelchairs at Orthofit. When I approached them, they said that the starting cost of wheelchairs is around Rs. 48,000

and in order to go to the advanced models I have to invest around Rs. 1,50,000. This is beyond my affordability (Harsha, 19 yrs old).

Women respondents report specific problems about availing free of cost ATDs at the IMS-ALMU.

The washrooms and training facility at IMS-ALMU are not PWD friendly. We have a washroom located at the dark corner of the room with no light. Moreover, we have to climb three stairs to enter it. The washroom is not usable by PWDs. It has an Indian commode. The side bars for support are not provided. How can one expect an amputee to use such washrooms? At times, we have to come to this unit with male escorts, where we can't enter the washrooms with them. Here we take the help of Ayah, but she herself is suffering from polio and I can't trouble her. What to do? We can't go to private organizations for ATDs as we cannot afford the expensive ones. All through our life we have learnt to adjust because we were born poor and continued to enjoy poor life style (Yadamma, 35 yrs old).

On the other hand, Pooja, 21 years old, reports that,

I was given my artificial limb at IMS-ALMU. They fitted and also taught me how to fit my leg on my own. They tested my walking with the help of a walker. I was asked to walk two rounds outside the unit. Inside the unit there is hardly any space to walk around. Later, they sent me home. I was told to train myself about how to walk and how to use the staircase without support. It was very difficult for me to train myself. Many times, I had to manage myself without falling down. When I asked the unit people to train me, the unit people asked me to come regularly for 15 days. I stay in Rajendranagar which is about 20 KM from here. How can I travel from that far regularly, as I can't use public transport and at the same time, I can't afford to come by autorickshaw.

It may be observed that the IMS-ALMU offers ATDs for free of cost, thus helping poor to access the ATDs. However, as highlighted by the respondents, the issue of obtaining documents/certificates emerges as the biggest challenge, particularly for the rural poor. Number of visits one has to make to obtain the ATDs from IMS-ALMU is the next biggest obstacle. The rural poor needy have to visit several times to procure the ATDs and get trained in using them. The poor coming from rural areas have to bear the travel expenditure, apart from the expenditure on food and accommodation in Hyderabad.

The next biggest challenge is the structural barrier. Although the IMS-ALMU is created to serve the orthopedically challenged the built space is not conducive for their use. This is highlighted by a respondent when she was narrating the access to washroom. It may be mentioned that the staff in the IMS-ALMU are neither sensitized nor aware of the special needs of the PWDs. A state funded institution functioning without making disabled friendly physical space is a matter of concern. Similarly, the study finds the attitude of the staff appears to be driven by charity mode which is a great barrier for the PWDs to access the state-run facility. Those who can afford go to Orthofit, a private institution, for-profit organization. They appear to be happy to utilize the services and training facilities from this organization.

Issues of Access to ATDs – Income and Regional Variations

Assistive technology devices are manufactured at IMS-ALMU located in Hyderabad. This organization provides prosthesis and orthotics free of cost to the persons with locomotor disabilities. Orthofit, a private run organization provides the same for cost. The study attempted to understand the issues involved in accessing the ATDs from both the organizations and attempted to analyze how class differences play an important role in accessing ATDs.

Table 5.4: Income and Spatial Categories of Respondents

Income category	IMS-ALMU	Orthofit
Low- Less than Rs. 2 lakhs per annum	21 (52.5%)	2 (05.0%)
Middle - Rs. 2 lakh to Rs. 6 lakhs per annum	6 (15.0%)	4 (10.0%)
Upper - More than Rs. 6 lakhs per annum	4 (10.0%)	3 (07.5%)
Total	31	9
Place of Living		
Rural	20 (50.0%)	2 (05.0%)
Urban	7 (17.5%)	11 (27.5%)
Total (out of 60 respondents of the study 40 are the users of ATDs)	27	13

Twenty one out of forty respondents of the study have availed the ATDs from IMS-ALMU and they belong to low-income category, i.e. with an annual family income of less than two lakh rupees. Six belong to middle income while four belong to high income categories and they all have availed the ATDs from IMS-ALMU. ATDs from Orthofit were availed by nine respondents in all. Surprisingly two respondents who belong to low-income category also availed from Orthofit. The study also finds that a large majority of the ATD users from IMS-ALMU are from rural areas. It may be suggested that the rural poor are referred to IMS-ALMU

to avail the ATDs and the respondents also mentioned that they come all the way from their home towns/villages to get the ATDs for free of cost.

Preference for Orthofit is also due to the aesthetics of the ATD. A young girl respondent who availed ATD from Orthofit, as she was able to afford the cost, mentions that she wanted to get an ATD which should not look obvious and attract unnecessary attention. To overcome stigma, she wanted to pay for the ATD. On the other hand, a respondent who is a poor rickshaw puller in Karimnagar town, could not afford the ATD from Orthofit and hence went for the IMS-ALMU ATD. Apparently the ATD provided by IMS-ALMU was of no use for him to pull the rickshaw and he said that he is now begging for his livelihood. A detailed view is presented below.

Aditi, is a 15-year-old girl hails from Hyderabad. She met with an accident resulting in an above-knee-amputation. Her parents, belonging upper middle class income category, could access information about advanced prosthetic device. For them, the cost of the device was a non-issue not just because they can afford. But also, that they weighed it against the social cost of disability, keeping their daughter's marriage in mind. The concern for the family was to be able to make her look normal and live normally. Eventually she was provided a prosthesis by Orthofit for which the family spent quite a huge sum of money. Using the advanced prosthesis Aditi was able to develop a natural gait. At Orthofit she received proper training for a month. She is now pursuing her higher education in a prestigious Women's College in Hyderabad and also claims to be doing her recreational exercises like before. Aditi's case presents us certain important social pointers. Aditi belongs to a well to do family for whom the girl's marriage and appearance were a priority. The family stays in Hyderabad because of which the family had access to information on the ATD providers. Her family could afford the full cost to get her exactly the prosthesis she needed, including the cost of its upkeep and maintenance.

On the other extreme is the case of Dhanayya. He is 35 years old living in Karimnagar pulling a cycle rickshaw for livelihood. He migrated to Karimnagar in search of livelihood from a nearby village in the same district. After a train accident his leg was amputated above knee. He desperately tried for an artificial leg so that he can continue to pull his rickshaw. His main concern was getting back physical ability to earn a livelihood and was not bothered about the physical appearance at all. As the chances of getting the prosthesis in his hometown were bleak, he approached IMS. For him, visiting IMS in Hyderabad was a challenging task as he had neither financial support nor family support. Eventually, after passing through the several

financial and procedural hurdles he was fitted with an artificial limb at IMS. Although IMS provided the prosthesis free of cost, he had to spend a lot of money on commuting to Hyderabad several times. After started using the prosthesis, however, he found it difficult to use because of lack of proper training he received at IMS and in his hometown. The device proved to be not of much use in terms of the expected functionalities, as a result he ended up not using it any further. The prosthesis could help him walk shorter distances but he was in need of auxiliary crutches for longer distances and climbing stairs which were neither affordable nor accessible. After some time, he had to abandon the prosthesis and ended up on the stairs of a temple in Karimnagar begging for his livelihood.

These personal experiences with the prosthesis points at several sociological issues, namely, affordability, identity, gender, poverty, access, the design of prosthesis itself. In both the instances the nature of disability is identical (above-knee amputation). The experience of gaining 'ability' through artificial limbs was conditioned by several social and cultural factors, apart from economic factors. The girl was able to lead a life of dignity, aspiring to become a role model for differently abled people, while the man who could not afford the best possible ATD was left with a permanently disrupted life.

Today's world is being redesigned and reshaped by technology like never before. Technology is redefining biological limitations in the PWDs, however, we must exercise caution in celebrating these innovations. Whose lives are being transformed? Is the cost appropriate? Are the rights to experience these innovations being relegated to higher classes? While ATDs can be a miraculous branch of medical technology, we must refrain from allowing them to be divisive in any way.

Gender and ATDs

Accessing ATDs is conditioned by gender of the users. The perception in many poor and middle-class families is that women do not need the ATDs as much as men since they don't go out for work or other family needs. Women with disabilities are often seen as home-bound with little attention to their interests or wishes. Several scholars have pointed out the double burden (Ghai, 2002) that women with disabilities face in India. In this scenario to what extent families are willing to pay for the ATDs for their women is an important issue to understand. This study, using the data collected from forty ATD users found a clear pattern in the use of ATDs on gender lines.

Table 5.5: Gender and Type of ATDs

Gender	IMS-ALMU		Orthofit		Total respondents
	Prosthetics users	Orthotics users	Prosthetics users	Orthotics users	
Men	9 (22.5%)	11 (27.5%)	7 (17.5%)	2 (05.0%)	29 (72.5%)
Women	3 (7.5%)	4 (10.0%)	2 (05.0%)	2 (05.0%)	11 (27.5%)
Total	12 (30%)	15 (37.5%)	9 (22.5%)	4 (10%)	40

Data suggest that nearly more than seventy percent of the ATD users are men. They have used the ATDs either through IMS-ALMU or Orthofit, compared to only twenty seven percent of women/girl users. In general, women with disabilities have different needs, just like any other demographic, but they are rarely seen properly as individuals. Each disabled woman faces a very different set of barriers depending on whether she has a locomotor disability, sensory disability, mental disability, or some combination of the three. Disabled women in India are still facing barriers with basic necessities like education, employment, food, housing, health and social exclusion. As a rule, disadvantages stack. A woman is already disadvantaged in India. If she is disabled and of a lower caste, then she effectively has three separate disadvantages that all affect her life both concurrently and separately (Ghai, 2003; Reddy, 2011; Mehrothra, 2013).

According to the Census of India 2011, among women with disabilities, fifty five percent are illiterates and forty five percent are literates. Nine percent of the women with disabilities have matric/secondary education and three percent of women with disabilities are graduates and above. About seven percent of the female disabled literates are graduates (Census of India, 2011).

According to the recorded information on the number of ATDs supplied in IMS- ALMU in 2015-2016 was two hundred and fifty. Out of this, one hundred and ninety were men and sixty were women. In Orthofit, the total number of products supplied from March 2016- May 2016 was one hundred and fifty. Of this, one hundred and ten were men and forty were women.

Data presents a stark difference between men and women users of ATDs. It was found in the study that men users of ATDs are more when compared to women. Prioritizing men is influenced by family. Family sees men as breadwinners. It was suggested that women with disabilities are rarely brought to the ATD providers. Among those women who are brought are

mostly in the marriageable age group. Married women, single, middle-aged women are not brought because the family does not see economic importance of the women.

Women are often denied expensive treatment because they are not considered to be economically important for the family. It was also found that parents as well as doctors believe that women with disabilities are involved in low productive work largely confined to home. Even if women with disabilities are taken to the ATD providers, the low cost ATDs are preferred by the parents. Doctors also aim for providing basic functionality for women as they seem to be carried by the justification parents/husband provide on the burden of the cost vis-à-vis economic contribution of the women. It was also reported that those parents who want to get their daughters married approach ATD providers to enhance not only functionality but also physical appearance in walking and standing so that alliances are found with easily with less dowry. It was reported by parents that there is a direct relationship between the extent of locomotor disability and the amount of dowry. Hence, parents aspire to bring down the locomotor disability using ATDs to cut down the cost of dowry.

In the words of a respondent

I lost my leg in an accident, I need an artificial limb to lead an independent life because I have a full life ahead. My parents can afford to buy an advanced limb, but they want to save money for my wedding as well as for my sisters' wedding. My father says this leg (provided by IMS-ALMU) is more than sufficient for me to lead an independent life. He says this because he believes that I am going to sit at home and I don't go for a job. But the ATD which I am using is of little use as it cannot bend properly and it is not flexible. My parents don't bother about my difficulties in using this locally-made ATD (Sirisha, 22 yrs old).

The choice of device should be up to the individual, but in reality, doctors continue to filter their suggestions through a person's social class using their own social prejudices. As such, many families never even hear about the full range of options available to them.

Education and employment are related. Education is necessary for advancement, especially for girls and women with disabilities, as this is where they learn to communicate their needs and interests effectively. Without a basic education, their chances at gainful employment and a productive lifestyle plummet.

Women face discrimination in employment with or without a disability, but women with disability face double discrimination. Along with the stereotypes on PWDs, some physical

work environments are simply inaccessible for those with disabilities. PWDs are subjected to mismatched skills, limited training, language barriers, and all the standard difficulties associated with entering a workplace. But the challenge of physically maneuvering to their workplace adds extra burden on PWDs. Girls with extensive physical disabilities have even less opportunity for schooling. Inaccessible school buildings have resulted in dropping out from schools.

One of the respondents Nikhila, 12 yrs. old, from Warangal reports that

It is very difficult for my mother to lift me up to the second floor to attend the classes. At times, due to prolonged medical treatment, I have to face a shortage of attendance due to which the only option left for me is to drop out from school.

Anuradha, a respondent aged 24 yrs. old, reports that

After my graduation I started looking for a job. My dream is to become a Group - I Officer. I was waiting for government notification. It's been years now and the government has not yet released notification. I didn't want to burden my family. I wanted to contribute to my family from my end. The only option left to me was to become a schoolteacher in my village in Khammam. However, the school buildings are not accessible for me as there are no ramps. Even using public transport is very difficult for me. Public transport is not disabled friendly in India and in a remote village in Khammam it is difficult to expect. Somehow, I manage to go to school. I have hired a rickshaw to drop me off and pick me up to the school daily. Probably this is the only means for me to travel to school. My own students look down upon me and call me with different names. They are highly insensitive. I knew that in cities and towns, people are a little sensitized on the topic of disability but I can't even shift to a town or a city to teach as I'm trained in my regional language Telugu.

Women in general are fed poorly in India. It is more in the case of women with disabilities.

A respondent Sri Latha, mother of a one and half year old disabled respondent says:

At my home, all the male members of the family eat first. By the time we sit to eat hardly we are left with any food of our choice. I do remember most of the times; I ate rice with water during the time of pregnancy. Neither my husband bothered nor my mother-in-law bothered to give me nutritious food. This resulted in giving birth to a disabled child with malnutrition. Now my family members including my husband blame me for giving birth to a disabled child. My in-laws look me down as if I'm responsible for giving birth to a disabled child.

Unsurprisingly, Indian women are often left out of decisions on both the family and community level. Additionally, they must endure the social stigma and the stereotypes associated with disability, including the religious superstitions rampant in rural parts of India, making them feel ashamed and, in worst cases, helpless.

One of the respondents Akhila, 15 years old states that,

I always like to attend social gatherings in my family, community but my parents neither allow me nor take me along. My parents often feel ashamed when my relatives ask them about questions on my marriage, my future and on. Most of the times my parents take important decisions related to me like, going out, what to read, which dress to wear, what to eat and on… without my consent. If I try to argue they often tell me that they knew what and when to do. To me, it seems like I have no control over my own life.

Society places a dangerously low priority on women's health. Health issues should never be hierarchized, but there is clear evidence that families and communities are significantly less willing to invest in women with disabilities than they are to invest in men with disabilities, both emotionally and financially.

One of the respondents Aarthi 27 yrs. old says that

Women with disabilities are often considered as unfit to take the biological roles of wife and. Even if they ever manage to get married, that is just because of paying large sum of dowry. Why don't my own parents, in-laws and husband keep in mind about my physical health? Why don't they even ask me whether I'm physically fit to conceive?

Both government-run and non-governmental organizations should have access to the most recent advanced technological methods. This includes upgrading the tools and machineries used in manufacturing, as well as replacing or re-educating the mostly unskilled workforce so that well-trained and qualified professionals who are aware of these issues of disability will be directly involved in development. The concept that an ATD can be one-size-fits-all must be abandoned. Developing cost-effective strategies to ensure that these technologies are accessible and affordable will be a challenge, but it must be undertaken.

Gender, Age and Class

Women with disabilities are frequently able to use the technologies available to them in their daily tasks for communication and mobility, but not many women are actively involved in

designing these products. Those who are undereducated or unemployed are unlikely to be trained properly, making it difficult or even impossible to pursue a career or education. Even getting access to proper ATDs requires access to information about how to pay for them. All the women respondents reported that they lack access to information and cannot afford the appropriate technology.

Nirmala (38 years old) expresses her regret for not being able to access high tech technology;

It is written in my destiny to be born as poor…. I don't have other option except for depending on the devices given by the IMS-ALMU.

Saheena (40 years old), states;

I was bound to the wheelchair as I was not considered as a breadwinner of our family.

Women and older respondents frequently reported that the products they were matched with did not suit their individual needs well.

Stigma and Assistive Technologies

Erving Goffman's concept of stigma connotes negative stereotypes on PWDs rooted in their physical appearance. According to Crocker et al, (1998) a stigmatized is "devalued, spoiled or flawed in the eyes of others. Thus, every human being irrespective of class, caste, gender, occupation, educational qualification might have experienced some degree of stigmatization at some point or the other point in their lives, whether it is feelings of isolation, alienation, exclusion or embarrassment resulting from being different in some way" (Parette, P. and Scherer, M.J. 2004).

The concept of stigma has been known to be associated with impaired bodies for many years. References to the phenomenon of stigmatization of individuals having disabilities may be found throughout literature (Goffman, 1963). Stigmatization has a direct correlation with assistive technology (AT) usage for persons with disabilities often resulting in the abandonment of devices. It may be said that persons with disabilities, irrespective of age may choose not to use ATDs like wheel chairs, canes, crutches, walkers, etc. fearing attracting stigma.

The present section attempts to understand the relationship between lived experiences of assistive technology device users (both prosthetic and orthotic) and non-users. Data include

forty ATD users and twenty non-users. It was found in the study that the degree of stigma varies between ATD users and non-users.

Using Hip-Knee-Ankle-Foot orthosis, Knee braces, walker, stick, etc., are perceived as stigmatizing by most of the persons. A women respondent, who is affected by polio, said about the need to wear hip- knee-ankle-foot orthosis:

When I want to wear the device outside my dress, my mother always says that it doesn't look good. My mother often says that I'm unmarried so I can't go out as I like. My outfits were specially stitched so that I can wear the device inside. My parents wanted me to undergo corrective surgery to remove this device permanently (Anusha, 19 years old).

Another respondent mentions:

The months that came [after being fitted with an ATD] *were demanding, the recovery and rehabilitation were long and slow. You never know whether you would be able to walk with assistance or without assistance. I was dependent on many orthotic devices like ankle foot orthosis, knee brace, and spine brace, walker and stick to correct my ankle deformity. Luckily the orthotic devices I used were temporary. I must be thankful and grateful to God. Though I limp I'm fortunate enough to feel that I'm not dependent on any devices now. I don't like when people stare at me. It makes me feel weird and uncomfortable. Slowly, I have recovered and now have only a little functional impairment* (Nisha Gopika, 23 years old).

The choice to wear assistive devices like a hip-knee-ankle-foot orthosis, knee braces, or using a stick or walker is influenced by social factors like attracting stare, stigma, etc. Using ATDs has strong implications for one's self-esteem. Preparedness for the use of ATDs is mostly psychological as the individual is influenced by what others feel about the device and physical appearance.

Related to the use of ATDs is the availability of associated services and the extent of accessibility of the built environment. ATDs are not always supplied with consideration for the associated services a person may need, such as training and repair. Substandard ATDs often require more maintenance than high-quality ATDs but often come with no such guarantees or recommendations. (Scherer, 2003).

The study finds that climatic conditions also play an important role in the use of ATDs. A respondent observes that:

I'm blessed to afford an advanced ATD called C-leg (a limb made with German technology) which enhances my walking without investing energy from my side. But one thing which often annoys me is the cloth used in between my stump (knee) and the artificial leg. The cloth is designed to bear the climate in cold countries like Germany. The cloth is designed in a way that it can sustain cold and can produce heat. India being a hot country, the cloth which is used in the stump makes me feel quite irritating and I'm developing wounds around my stump which is very painful (Ramesh, 38 years old).

Aesthetics, Prosthesis and Orthotics – Personal Satisfaction with ATDs

Saradijan, Thomson, and Datta (2008) refer to the adjustment period as a personal process, different to each individual. Acceptance is gradual and comfort levels can differ. Following are observations regarding this adjustment process from the respondents.

You need to adjust the prosthesis by wearing it for limited periods of time initially. Then you start going for short walks. When you stand for long hours, you have to bear with back pain (Pranay, 28 years old, prosthetic user).

You need to trust your body. You must trust the other leg so that you can stand on it and walk. You can't remain dependent on crutches or a wheel chair for a lifetime (Padma, 20 years old, Prosthetic user).

The hip-knee-ankle-foot orthosis is such a large device that you cannot handle the brace. Since it is not flexible, you have to carry such a heavy weight along with your leg. In summers, I develop skin sores around the entire leg. Since I have to wear it inside my leg, my outfit is specially stitched as I don't get ready-made outfits (Anusha, 19 years old, orthotic user).

I like to wear the traditional Indian attire, saree. Whenever I wear a saree, I try to see that my deformed parts are covered properly. It is not only about covering but makes me very uncomfortable while walking. I want to wear a saree but I am afraid of falling down (Preethi, 23 years old, non-AT user).

Respondents expressed their unique means of adjusting on an individual basis. Some customized their ATDs or started by using it for short periods of time. Common complaints included discomfort during hot Indian summers, due to the added weight and increased sweating. The study of Sardijan et al (2008) cited similar complaints, including skin sores caused by wearing prosthetics on hot days.

Emotional Reception

Respondents were asked to reflect up on their experiences with regard to the emotional and psychological reactions to the use of ATDs. Respondents shared their own reactions to the amputation and to the ATDs they attempted to use, as well as the reactions of close family members.

Self-Image

Respondents revealed the experience of amputation and usage of ATs is related to one's reaction to his or her amputation and using ATDs. Horghan and Machlachlan (2004) cite several factors that can affect a person's reaction, such as age, education, social class, the type of amputation, and even the time since the amputation. The respondents described their initial reactions to their amputation negatively. Padma, 20 years old, recalls;

Initially it was a huge shock. I was confused to see my missing body part and I really cried for my helpless situation.

Anuradha, 24 years old, observes;

When doctors asked me to use orthosis for lifetime, initially, I was always conscious about what others were thinking about me.

Generally speaking, respondents were shocked and dismayed, though some did take the situation more gracefully. Mounica, 21, managed to perceive her loss in a positive light:

The metal rods encircling my defective limb were both visually unappealing and physically uncomfortable. As a child, the first thing I asked my mother was whether the amputation would allow me to wear high-heels and other types of shoes; in this regard, I would say the amputation was ultimately a positive change.

It was reported by the respondents particularly by amputees, AT users and non-users, that they have experienced a long-lasting emotional distress such as depression and anxiety before they came to terms with the situation. They realized that they had to live with it. This could be due to heroic cheerfulness and strong willpower after overcoming the death-like situation.

All the respondents including ATD users and non-users are aware of the changed physical appearance with the loss of limbs and usage of ATDs. Miller and Deathe (2004 cited in Grench and Debano, 2014) highlight the importance of aesthetics and the impact amputation can have

on a person's self-image. Women respondents, especially, wanted to know that they would be able to still wear feminine clothes, such as heels and sarees. Men, by stark contrast, were mainly concerned with their ability to work and support their families.

Aditi, 15 years old, states that

Being a woman, I want to make sure that the prosthetics look appealing, especially if I am wearing a skirt.

Veerababu, 35 years old, also describes how his pride was affected.

It made me feel inferior, because I could no longer be my family's breadwinner.

It indicates that men place more importance on the functional aspect of the limb and their ability to provide financial support to their family.

Perceptions of the Significant Others

Respondents described the reactions received from their close family members after losing their limbs. Veerababu (35 yrs old) explained that his daughter initially seemed to be afraid of him, though she came around and quickly realized that it was still her father. Mounica (21 yrs old) highlighted her mother's discomfort, pointing out that her mother had often been preoccupied with the judgmental comments of others.

Pranay, 28 years old, describes his experience in the following way.

My parents took it really badly. Especially my father, who had never wanted me to ride a motorbike for fear of accident.

Nisha Gopika, 23 years old, describes her mother's distress as follows,

Every time I cry, she cries with me.

The difficulties parents faced mirrored the difficulties that their children endured. In fact, many of the respondents, both parents and those with disabilities, were just as eager to bring up how the situation affected each other as they were to speak about their own struggles.

Lifestyle Changes

Findings from the study uniformly point at extreme and mostly negative changes in lifestyle as a result of amputation. The respondents who underwent amputation reported a significant loss

of independence, at times leading to feelings of helplessness as they were forced to increasingly rely on others.

It's really difficult! You have to depend on many people including strangers at times. I hate it when I can't do something myself (Saheena Kathoon, 40 years old, wheelchair user).

Those who previously enjoyed sports and other physical activities specifically cited the absence of those activities as stressful and emotionally debilitating.

The worst thing of them all is imagining not being able to run and play with my children (Veerababu, 35 years old, prosthetic user).

Assano, et. Al. (2008) found that mobility was a major predictor of an individual's quality of life following a lower limb amputation. This study supports the observation, as the respondents point out several ways in which a loss of limb led to decline in the quality of their life.

Social Exclusion

Importantly, many respondents felt a sense of social exclusion. They described coming home with a mixed experience in which everyday life suddenly represented many challenges, with their homes suddenly becoming inhospitable. Ordinary parts of the home became obstacles and barriers. Wheelchair users, in particular, could find their home life unmanageable if care was not taken before their homecoming to adjust the environment for their new mobility needs.

Everything took more time. Everything was more challenging. Household chores went from being a minor inconvenience to being a burden. Simple tasks, such as fetching a glass of water for a child or grandchild, became laborious and daunting. Favorite chairs and other resting places became inaccessible.

After Amputation, everything becomes difficult…. It is very painful when my grandson asks for a glass of water. I can't get it for him. I have a bloody wheel chair that doesn't fit into my kitchen (Saheena, Kathoon,40 years old).

Physical mobility and a person's sense of freedom are deeply interconnected. Being unable to live at home comfortably, or to even move around the home freely, contributed to a comparison between the home and a prison. These sentiments were strongest among those relying on prosthetics and orthotics like wheelchairs, who reported nearly unanimous feelings of confinement.

For me, watching television, reading, moving in the house doing bits and pieces is an easy task yet I'm confined to four walls. I lack confidence in using other leg and going out (Mounica, 21 years old).

Social Intervention

Social acceptability, especially within the family, deeply affects whether a person will continue to use an AT or not (Pippin and Fernie, 1997). Families from rural backgrounds may prioritize immediate results shortly after ATDs are prescribed, but this desire for instant rehabilitation usually proves unrealistic.

Anuradha, 24 years old, explains:

It took a lot of time to digest in my mind that in order to walk, I have to depend on my orthosis for lifetime.

Akhila, 15 years old, says:

It looks odd to use a wheelchair at my age when everyone of my age is walking around me.

Nisha Gopika, 23 years old, states:

When the doctor asked me to use a walker after my surgery, I was worried. I thought I should depend on this forever to walk. After a few months, I started walking with a stick, then my relatives were like, "Oh! You can't walk without a stick." Finally, after a lot of struggles I started walking without assistance of ATD. Then I was like thank God! I'm finally walking with my legs without any additional support.

However, respondents were quick to point out the importance of support, especially from family and friends. Social support within their peer groups and from the staff members at the hospital had a profound effect on the perspectives of the respondents, with many implying that this support was one of the most important aspects.

Family and Friends

Respondents took on new unfamiliar roles as passive observers and receivers of help, at least initially. Unable to perform their previous roles, they often developed feelings of inferiority. This, in turn, damaged their self-image and sense of dignity, even in deeply personal relations. However, respondents did point out the importance of re-integration and the role that being socially active played in their recovery. Williams et al. (2004) report this as an instrumental

part of readjusting after loss of a limb, and the respondents seem to confirm those assertations. As Padma, 20 years old, explains;

Re-integrating after a long break can be difficult and time-consuming, and I believe that if you take too long to do so, you may experience negative consequences. I made an effort to reach out to my friends and family members, and even though it was not always easy to get back into my normal routine. I found it important to maintain my social life.

Family members tried to encourage the amputee during rehabilitation. Mounica (21 yrs old) says;

I was encouraged to abandon my mobility aids as time went on, with family and medical professionals applying pressure to rely on the prosthesis.

Other family members facilitated the coping process, as described by Pranay (28 yrs old);

I was fortunate that my father was able to customize my prosthesis by affixing an electric motor that has been of great assistance.

Support is considered to be important, but sometimes respondents felt they were being over-protected by their families. For instance, Nisha Gopika (23 yrs old) recounted the following episode.

The Last time my mother observed me ascending the ladder, to replace a light bulb. She became distressed and implored me to descend due to the fear I would fall.

Perceptions on Self-Image

Respondents consistently reported that amputation had changed how they viewed their own lives. Common themes included the need to establish a new role, the need to accept a different lifestyle, and the willingness to become whole again. Focus was placed on the immediate future rather than the long-term future. The transitions took time and were described as mentally exhausting, with every little movement representing a new challenge, while the lack of trust in their physical body led to a loss of balance.

I used to easily stand on one leg. I can't even balance now. I can't stand on one leg at all. (Pravallika 18 years old).

Feeling safe and secure was an instrumental first step in building the courage to try ATDs. The difficulty to maintain balance discouraged most respondents initially, with confidence being a major roadblock between the patients and the reacquisition of physical ability.

Some respondents managed to find hope within amputation, seeing it as an escape from a worst-case scenario.

I couldn't walk properly because of the pain. It was constant and I was afraid of even going to bed, because I would wake up minutes later in so much pain. It was a nightmare and something had to be done (Veerababu, 35 years old).

Respondents tried to maintain optimism, even as they struggled to find a sense of willpower and stamina in their daily lives. They remained determined to regain some of their mobility and, with it, their freedom. Unfortunately, they were forced to confront the changes in their own bodies. Their path forward required an expansion of personal boundaries, but every goal achieved helped to inspire new confidence in the respondents as they struggled to regain some feeling of control over their former territory and mobility.

My goal is to return to work someday. Even if people call it unrealistic, I have to have a goal. Otherwise, I would just give up (Pratyusha, 25 years old).

Prosthetic user respondents experienced a sense of hope that they would be able to return to active lifestyle. They were eager to return to some sense of normalcy.

My aim is to be able to walk again with the aid of a prosthesis. I am cognizant that I will likely not be able to achieve this entirely on my own, yet I am determined to do as much as feasible. (Mounica, 21 years old)

Treatment delays and unaffordability often represented major complications, putting indefinite holds on the respondents' ambitions and opportunities to return to a sense of normalcy. Unaffordability was experienced as a sort of vacuum in which life and time were frozen, on standby. This situation was challenging and negatively influenced respondents' ability to maintain their optimism and willpower.

A respondent's quality of life often depended on whether they were receiving the right type of help. Vehicles were mentioned in particular, such as automobiles and tricycles, as ways of reclaiming some degree of personal freedom. Those who were unable to live independently due to lack of such amenities felt especially cut off.

*Despite having my wings are clipped, I still want to explore the area I grew up in, to traverse around the block. I want to explore my neighborhood independently (*Pratyusha 25 years old).

Access to Professional Help

Healthcare professionals, such as doctors, nurses, physiotherapists, orthotists and prosthetists were also perceived as important sources of support. Respondents seemed to value different aspects of support when describing their experience in hospital.

Healthcare professionals were seen as important in supporting the respondents' recovery, often second only to the support from their own families. Respondents seemed to have different expectations and experiences in this regard.

Akhila 15 years old described the hospital staff as follows:

I cannot complain about anything. When I was in the hospital, I had good support because I had doctors, nurses… they were all supportive. They were always there to help change my dressings and provided for my needs.

In contrast, Padma 20 years old held a very different viewpoint.

Nothing! While in hospital I found no emotional support at all. They give you hardly any information on the procedure, the way it will affect your life and how to cope.

As you can see from the above, reception was mixed. Some respondents felt properly taken care of while others felt dismissed. All participants felt that physiotherapy was an important step following their amputation.

They all give their 100% to see you satisfied…they provide the support that you need. They see you as a person and not a number (Nisha Gopika, 23 years old).

Eldar and Jelic (2003) reported that early involvement from health professionals is key. Having access to advice on the options available, as well as the expected process, possible exercises, etc, is critical to the patient's experience.

Respondents found it challenging to face the emotional and lifestyle implications of losing a leg. They generally reported that professionals were only willing or able to help with the physical aspects and were not equipped to help them with the mental hardships associated with their new disabled status. This often led to feelings of loneliness in the respondents, who felt

they were only being provided with necessary and mandatory care, but not the emotional support they needed.

It was found in the course of field work in the hospitals that the medical field's hierarchical structure is often detrimental to the patient's best interests. A patient being supported by nurses, orthotists, physical therapists, etc., is ultimately left entirely to the whims of a main doctor, who may send the patient from department to department without a clear idea of what happens in the other departments. This only demonstrates the need for holistic education to the medicine graduates and specialists in higher level medical education sensitizing them on the issues of PWDs and rehabilitation process.

The doctor may not know about the materials in the proposed ATDs or about which prosthetics are most suitable, but there is limited communication between departments and ranks in the hierarchy, leaving everything to the doctor, even though all of the information about the case would often be right in front of the medical staff if they acted as a cohesive team of equals instead of a hierarchical ladder system.

It should be argued herein then that communication needs to be a priority of the medical staff, as the current systems tend to be insufficient in getting patients in and out with satisfying results. Patients, physiotherapists, nurses, the doctor, and administration should all be directly involved and directly communicating, so that cases can be concluded safely and with positive results that may lead to less abandonment of ATDs and more faith in the medical system in general.

Conclusion

The anxieties and experiences of the respondents discussed so far are placed in the following Table in a concise manner.

Table 5.6: Disability, ATDs and the Respondents' Perceptions

Themes	Perceptions of the respondents
Aesthetics	• Attracting the attention to the lack of limb leading to the fear of being stigmatized • It also involves the process of acceptance and adjustment on personal front • Orthotics like braces are perceived as stigmatizing
Emotional Reception	• Feelings of shock, sadness and surprise • Depression and anxiety, feelings of compulsion to use the devices

	• Feelings of being different in physical appearance
Lifestyle Changes	• Changes in lifestyle after amputation • Discomfort in using prosthetic devices, even at home • Discomfort while using orthotics while accessing public spaces
Social Exclusion	• Home as confined space • For instance, I can't move straight away from my bed as I can't balance on one leg • Feeling of guilt while using a particular device, public spaces cannot accommodate their devices (For instance, wheel chair users) • Feeling of being different from non-disabled, due to deformed body parts
Social Intervention	• Family, peer and professional support is mandatory to train using the ATDs • Social acceptance of artificial limb by family members plays an important role • They had a feeling of the social accessibility of the devices- for instance; their intention is always to cover their device in order to look normal when they go out
Perceptions on Self-Image	• Family support and economic affordability inspired them to try new devices • 'Hope' and 'Will' are the as major driving forces • Being positive
Gender, Age and Class	• Feminine appearance and the ability to dress properly and attractively was cited as important among women/girls • Men/boys prioritized their ability or inability to work. • Being a breadwinner of the family men could opt for more technologically advanced or imported Assistive Technologies than women. • The under educated or underemployed woman, and girls having more than two siblings are unlikely to get the technology or training necessary • In general, women with disabilities considered to be doubly oppressed • If the woman belongs to lower caste/ class uneducated/ under employed/rural/urban, she is considered as triply oppressed or multiple oppressed

CHAPTER 6

Conclusion

Family, school, and workplace have emerged as the most important spheres of social life in modern time. However, these spheres of social life are conditioned to suit the interests and needs of 'normal' ignoring the special needs of the PWDs. How persons with disabilities make sense of these normative structures, how they negotiate the social, cultural, economic and technological embeddedness of these structures, how these structures can be democratized particularly with reference to PWDs are some sociologically relevant questions arise in the academic domain and activist's agenda.

The everyday experiences of persons with disabilities in accessing and negotiating assistive technologies (ATs) is a matter of academic as well as policy interest as regards PWDs. The present work attempts to explore these issues in detail. Construction of identity in persons with orthopaedic impairments, especially in regards to how they perceive themselves and how they feel they are perceived within society is as important as studying the access of ATs. One of the main objectives of the study was to bring out the nuances in the integration of ATs in the lives of orthopedically challenged.

The framework that guided the present research integrated a combination of the most modern models, especially drawing its perspective from critical disability studies, the interactionist perspective, and the elements of the social model of disability. To elaborate on the latter, disability is seen as "socially constructed" (Oliver, 1996). Critical Disability Theory (CDT) is built on the ideology of critical thinking, analysing the world around us and envisioning it as it could be rather than what it is. CDT, then, places emphasis on PWDs as well as social world that accentuates exclusion of PWDs.

The roles a person play, including one with disability, are fluid and multiple. They stem from society and are in many ways embedded into factors beyond one's control, such as gender and class, but disability exists as a sort of extra, often inhibitive identity, influencing the roles performed by PWDs. Those with disabilities are often treated as belonging not to any of the roles into which they feel like they should fit, but as if they can only be seen as disabled. This, among other factors, will need to change rapidly in coming decades.

The future is promising, though. Since India first started participating in the Paralympic games, the number of medals our country has won has been steadily increasing; with the 2020 games

being the best show by far. This demonstrates that the medallists have been receiving better support and recognition than ever before and it should be seen as a victory for both the individuals and the progress of the country in its empowerment of those with disabilities.

The field work for the present thesis was conducted in Hyderabad city. Respondents were selected from the two medical units (one state medical institution, and the other a private ATD providing unit) located in Hyderabad, and data were collected for a period of five months through personal informal interactions. Respondents comprised of sixty persons with disabilities, both men and women. Out of sixty respondents forty respondents are AT users while twenty are non-users. The age of the respondents ranges from one year to forty years. The study broadly focused on identities and ATDs. Parents of the respondents were also interviewed to ascertain the perspectives of family members offering critical support to PWDs. As discussed in the previous chapter, the respondents' experiences and their outlook to ATDs differed based on class and gender. Parents' responses differed widely depending upon their education, occupation, and income.

Understanding Disability: The Perspectives of the Significant Others

Disability connotes disadvantage, that results not from the impairment but due to the social construction of the concept. The term "disability" refers to socially ascribed meanings that describe diverse human conditions, having different types of physical and mental impairments throughout life in different cultural contexts (Mehrotra, 2013). Disability need not always give rise to handicaps but several inequalities that exist in society make disability and handicap appear as inseparable. Due to this, disability in individuals becomes a hindrance on their way to progress and prevents them from taking the lead in all major roles like other individuals. The most common perceptions of disability are deep-rooted in our shared socio-cultural history.

PWDs constitute a highly marginalized group. Children with disabilities are seen as objects of pity, rather than as their own people with their own ambitions and needs. It's not uncommon for disability to be seen as inferior. In rural India, especially, children can even be abandoned at birth just for being born with a disability. This only happens because of the prevalence of negative attitudes toward persons with disabilities among the general public.

Parents are expected to feel ashamed and become unable to envision a hopeful future for their disabled children, and they also confront the fear of social isolation. Religious beliefs in India often associate disability with punishments for the misdeeds of a past life. Children with

disabilities are hidden away from the public gaze. Even when they do go out, environmental barriers can make it hard for them to function in public spaces (Paterson and Hughes,1999).

Karma, as a superstition, is partially responsible for the reluctant acceptance of disabilities. Indian families still go through the same stages of trauma and grief, but they then accept disability as a part of their child's fate. Recuperation services are not widely available in India, so even children with lifelong disabilities often find themselves with no recourse. Due to economic and educational limitations parents are helpless to find access to services that could help their child.

In India, a child is seen as an investment. A child with a disability cannot provide labour or income in the eyes of the parent. As such, there is an emphasis on spending the limited funds the family has on their healthy children, and especially on male children who can navigate India's patriarchal society more easily. In India, man is considered to be the breadwinner of the family. There is also a quiet bias against those born disabled.

Disabled, like other marginalized groups, are excluded from the mainstream society. Persons with disabilities experience social stigma. Individuals tend to be evaluated more based on categorical membership to these marginalized groups than on their own characteristics. The disability trait overshadows and qualifies all other traits and abilities (Wright, Betraice 1964). Often, persons with disabilities are deprived of necessities such as education, employment, and transportation (Ghai, 2002; Mehrothra, 2013). This is due to attitudinal barriers, manmade environments, and the societal divides. The disabled are prevented from participating on par with their non-disabled peers. Societies are only just now noticing the systemic injustices against disabled people, so the problems and barriers of the past are being torn down, but it is unfortunately a slow and gradual process (Cole et al, 1996).

The data from the study suggests that the parents of respondents frequently underwent extensive financial and physical strain, especially early on. They attempted to search for some solution or cure at first, but often ended up settling for coping strategies that would minimize stress and conflict. Coping strategies did vary with the socio-economic status of the families; with well-educated and wealthy families devoting much more of their attention to seeking out solutions in terms of advanced ATDs, medical specialists and physiotherapy sessions.

Parents across the board did whatever they could to secure treatments and/or cures, given the knowledge and resources available to them. Families who were more vulnerable, due to lack of finances or education or both, did what was possible with their limited means. The lack of

resources often made such families feel helpless, leading them to withdraw from treatment and resign themselves to an unkind fate. In some cases, this was due to having to weigh the ongoing cost of treatment with the various other financial responsibilities of a family arising out of social pressures like marriage of the disabled girl child.

The presence of children with disability had a significant negative impact on the family life. Parents and siblings felt affected by the longer engagement required in the day-to-day care of a family member with disabilities. The parents specifically mentioned the health problems that they themselves developed due to the physical burden in taking care of the disabled child. A respondent's father, in particular, mentioned the death of his spouse, which he attributed to the mental pressure and physical strain caused by the disability of their child. Many families not only had no enough hands in the household to handle the physical and financial stress, but also were unable to procure such assistance given their poor economic status.

A majority of the parents did attest that their children were socializing and making friends in schools, or even out in their neighbourhoods. They would visit relatives during special occasions, such as reunions, marriages, festivals, etc. It should be noted, however, that their level of interaction with others varied depending on the type and severity of their disability. Those who were less dependent on ATDs like wheelchairs and crutches could go out and socialize, but those who were more dependent typically had to settle for whatever time other family members could make for them to go out.

Despite the physical limitations of their children, parents still had high hopes for their children. In the early years, an emphasis was put on diagnosing and treating the cause of the child's impairment. Later on, the focus would typically shift to planning for the child to have a good education, lucrative career and marriage. Parents generally expressed a feeling that having those elements in their lives would help their children to cope with any hardships that disability might impose on them.

Marriage, especially, was a priority topic for many of the families interviewed. The parents of both sons and daughters reported apprehensions about marriage, fearing potential abandonment or exploitation, but mostly agreed that marriage is an important part of life that they felt their children needed to be able to experience. A majority of the parents of the girls aspire to get their daughters married, considering marriage to be a social security for women in India. They were, however, concerned about the potential consequences of childbirth, child rearing and domestic work given the problems of impairment. Thy worried that their daughters would be

seen as incomplete persons, a notion that also harks back to the double disabilities concept (of being both female and disabled) proposed by Ghai (2002). Some respondents were also afraid that the impairments would be genetically transmitted.

The impairment of children is usually detected early, from immediately after birth to roughly two years of age. Majority of the children who suffer from orthopaedic impairment are those who were not given the polio vaccine. Parents of these children attribute it to lack of awareness on polio vaccination. Environmental factors such as poor health and sanitation standards, along with inadequate pre-natal and post-natal care, seemed to be especially relevant. One thing found to be consistent across the interviews was that many who were born with disabilities had been born in families that offered subpar nutrition to the mother during pregnancy. This helps to illuminate a potential cause of disability in rural areas that should be further explored.

There are popular beliefs and superstitions in India that those with birth defects are being punished for the sins of the parents, or that curses upon a pregnant mother can lead to a child with disabilities. The study does find parents who hold such notions. However, some parents mention Karma or fate as a potential cause of disability. Most of the parents show faith in their children, believing with a positive outlook that their children would be able to find a place in the world regardless of their disability.

The need to use technology to overcome deficiencies and defects does not represent a desire for perfection. It represents a desire for happiness within realistic limitations. A disabled person's desire to live better is less about becoming perfect and more about becoming included properly in discourses and activities.

Disability should not be seen as just a medical condition. It is a human condition. It is an issue of perspective and disability must be recognized as an inalienable facet of the real world. Anyone can become disabled. Humans are frail and we build societies in order to protect ourselves, so we should be able to expect these societies to reciprocate our needs. Our lives are already supported via artificial creations every day. Vehicles to pass increasingly large distances. Computers to communicate remotely. Overcoming disability is just a microcosm of what technology has always worked toward, and should be prioritized.

The discourse about disability is a telling part of understanding the human condition as a whole and how we understand our limits, both socially and physically. It is possible for persons with disabilities to achieve an effective level of equality within society if society is built with their

needs in mind. Right now, that means rebuilding portions of our society, but this is not beyond our means or our abilities.

Technologies can, in many cases, be thought of as an extension of our own human limbs and organs. Think of how a person "fits" in the driver's seat of a car, thus completing a larger mechanical body. However, the social world sees differently when it comes to technologies related to disabilities. The human-technology interface is mediated by social norms with relation to ATDs for PWDs. Such terms like welfare and care emanate from the social stereotypes based on charity and pity which is problematic for the scholars of disability studies.

For the orthopedically challenged, the loss of mobility disrupts lives in several ways. Not just a sense of exclusion felt by the individual, but equally by the families of persons with disabilities who face the social and economic degradation of the family. This study illustrates how the lack of freedom to navigate different social spaces deeply affects the lives of those with disabilities, especially in cases where wheelchairs or similar devices were mandatory for daily life. It was also found that ATDs usage in general follows a trend that mirrors the stigmatization felt by those using it.

It was found in the study that respondents are abandoning the ATDs after sometime. Research suggests that the abandonment of devices is often due to the discomfort or lack of training. An improvement to the overall systems that provide ATs, with more emphasis on quality control and training, along with a more team-oriented structure in providing professional assistance to persons with disabilities, could potentially go a long way toward addressing these issues. What comes out clearly from the study is that although the ATDs are made available free of cost to the poor, the supportive training and physiotherapy is still under 'paid' category. The respondents from poor financial background have clearly mentioned the prohibitive cost of physiotherapy sessions during data collection.

Additionally, some assistive technologies (such as wheelchairs) require accessible environments in order for them to function. Incompatibility with the environment can result in abandonment of ATDs and a loss of faith in them. Wheelchairs must not be substandard and should be provided with at least a base level of training in their long-term use and maintenance. Lack of training can lead to dangerous scenarios in users.

Universal design may offer a significant amount of relief, provided it incorporates the needs of as many as humanly possible. If goods are manufactured to be usable by all persons, then the stigmatization associated with using products made exclusively for those with disabilities may

diminish naturally over time. Little or no attention is currently paid to the aesthetics of ATs. It may be prudent to treat ATs as if they were both accessories and necessities, updating them to be more appropriate to the user's emotional needs. Female users of ATs especially seem to have a distaste for the 'ugliness' of the devices, which is an addressable problem.

More research is needed to explore the current and ongoing government policy related to ATs, but the research conducted thus far shows that India and the world at large are moving forward with more proactive plans and strategies. One notable concern with state-led assistance is that the government units tend to be far behind in technological developments. Units designed by privately financed companies tend to show much more promise and allow their users to think beyond limitations. Research found that many of these more expensive technologies are being imported from foreign countries such as Germany, UK, Taiwan, and USA. A majority of the potential users of ATDs cannot afford such foreign devices and the study reveals that roughly about forty nine percent of the participants are currently facing problems with accessibility and affordability services. The lack of economic means seems to be a primary barrier to both the end-users and the providers of ATs.

Stigma attached to AT usage is especially high among women, possibly in part due to the aforementioned aesthetic issues, but also due to the expectancy that women will spend most of their time working in the home. While it should be understood that this is a hesitant conclusion, it seems as though the financial constraints placed upon families dealing with disabilities and health providers do need to be alleviated in some way. The furthering of technology, for example, will only help insofar as that technology is made affordable to the end-user. Government-led assistance programs, which ultimately mean well and are making a conscious effort to expand, still require funding in order to increase their influence and reach. Additionally, it would not be possible to campaign for increased awareness of the issues without some base level of financial investment.

As such, the budgetary allocations for disability issues need to be reassessed. Make no mistake that human effort and the natural progression of ideologies will go a long way toward improving the lives of those with disabilities, but in order to hire more human resources and further the development of the necessary technologies, it will be important that the budgets are examined carefully on both governmental and institutional levels.

On the humanistic side, society will need to continue to advance towards a universal approach to design. Constructed environments such as schools and workplaces, as well as basic common

goods like bottles and cans, need to be purposely designed with the full scope of human experience in mind. If a product is not usable by an elderly person or a person with disabilities or a child, but is intended to be accessible to all three, then it needs to be redesigned with universal design principles at the forefront. Even the resources used to produce the devices are often restricted or limited, making acquisition difficult not only at the end-user level but at the more basic level of manufacture. There have been initiatives and government schemes in the most recent decades that aim to reduce the severity of these problems in India, but it is difficult to say whether these gradual improvements will keep up with the increasing demand as populations continue to increase.

In the current study many respondents specifically pointed out problems with the levels of documentation that were asked of them by the AT providing units and the physical distance between their homes and the medical facilities they could access. Lack of prior information on the documents required for accessing the ATDs has been pointed out by many respondents, particularly those who are coming from rural areas. Cost of the devices has been a deterrent to many poor respondents. Those with the means could secure high-quality prosthetics. Meanwhile there were others who were forced to spend large portions of their savings and income on securing the ATDs, however, had to settle for devices that were of a lower quality.

Even among those who accepted assistive devices as a part of their daily lives, many felt unsatisfied for various reasons. These ranged from inability to work while wearing the prosthesis to feeling as though it hurts their self-image, to having difficulty adjusting to the use of assistive technologies, often coinciding with a lack of proper training in usage. One key common factor found in the study was communication breakdown across the board. If doctors, nurses, physiotherapists, administrators and users had ways to communicate with each other openly, it’s possible that some of these problems could be avoided.

Another problem is the under-valuing of physiotherapy. Government programs currently do very little to make physiotherapy accessible, despite the prominent role that a physiotherapist plays in helping a patient to recover post-surgery. Often physiotherapy is not provided long enough or at an affordable cost to the patient, and with little regard to the necessary rest period following a major surgery. ATD users are forced to pay Rs. 1,500/- to Rs. 3,000/- per session and these sessions extend for 3 months or even beyond for a full or partial recovery. Many respondents found to be giving up the idea of undergoing physiotherapy because of the prohibitive cost of the treatment. It was also found in the study that physiotherapists are heavily

incentivized to offer in-home services, since hospital fees do not correctly value their labor nor the amount of time they will need with the patient. However, in-home services of physiotherapy are out of bounds for respondents coming from poor and rural areas.

ATD users are often left relying entirely on one main doctor, despite the fact that an entire medical team is present and could be communicating the needs of the ATD user to each other more clearly. Similarly, the documentation issue that came up with multiple respondents could have been avoided if they had been given a list of documents to bring before physically traveling.

This study is only a microcosm of the greater world of persons with disabilities and represented only some dozens of voices in one city. It needs to be said that this is an issue that affects families across the whole of India, and especially its rural stretches, so it is imperative that we address these problems to reduce the painful cascading effect that the family feels when one of the members is being excluded from society.

Critical thinking begins when we stop accepting that the '*world is what it is*' and recognize the need for the world that is needed if we take steps to change it. This is true of any and all human conditions, and this willingness to look past the existing world and towards a possible one that carries the spirit of Critical Disability Theory.

Reassessing our current understandings of physical structure, social structure, budgeting, and medical care will serve to improve the experiences of all persons at all levels, not just those with disabilities. Many persons with disabilities are not currently being utilized to their full potential, in the workplace or otherwise, and can contribute economically and socially to India's future if their needs are better met.

Increasing awareness and putting programs in place to curb ignorance of disability issues will naturally lead to an improved societal and national interest in improving the situation. In order to better address the needs of those with disabilities, the populace must first be educated in what these problems are and how far-reaching their effects are.

Recommendations

Sociology and Disability Studies in Schools

Sociology and disability studies should have a more significant presence in the school curriculum, not just at higher levels but even at the secondary school level. While personal

values such as acceptance and equal rights should ideally be taught in every home, it should not be assumed that every parent has the time, capacity, or willingness to provide their children with a robust understanding of the importance of acceptance.

This discrepancy (on social construction of disability) is one that teachers could help to alleviate. While studies of ethics must be carefully monitored at the administrative level, so as to introduce as little bias as possible, it should be acknowledged that the issues faced by PWDs will ultimately enlighten the future generations. The societal and structural limitations faced by the PWDs should be presented to students early on in life, so that they can enter the adult world more equipped to repair outdated systems and dismantle social barriers than preceding generations.

Institution of family and Shaping Attitudinal Barriers

Of course, we should also encourage families to take responsibility for the emotional health of their own family members, treating those with disabilities as equals rather than as victims or burdens. It is ultimately the family unit that is responsible for a person's emotional health and attitudinal barriers, so we must make an effort to educate the families in general and families of persons with disabilities particularly in this regard. Rather than sympathy, acceptance would be preferable. It should be understood that a disability is only a difference. Above all, society must shift in ways that encourage these families to be gentle and helpful, instead of pitying or being critical of their own family members.

Inclusion of Disability Studies in the Medical Curriculum

One issue that seems apparent is in the still-existing divide between the medical and social models of disability, as well as in the over-specialization of fields. While it is obvious that the different branches of medicine require entirely different skillsets, it seems disparaging that so many doctors and nurses are unaware of the greater implications of disability, having been only taught some variation of the medical model of disability.

It can be argued thus that those entering medical fields should be required to take courses in sociology and disability studies. It is necessary for all medical practitioners, doctors and paramedical personnel, to have a sociological understanding of impairment, disability and stigma. They should also be able to empathize with the condition of the PWDs and the social and physical constraints in using ATDs. The study finds that the doctors (and paramedical staff including ATD developers and physiotherapists) are not aware of the social (including cultural

and economic), physical and emotional trauma of the ATD users face. The argument is not that doctors are uncaring, but that they are not being given the sociological perspective on disability before they are set out to provide treatment. The sociological perspective relies on equality, equal rights and equal opportunities for persons with disabilities. A doctor who also has a sense of disability studies will be more acutely aware of the issues faced by PWDs and will be able to address the problem positively. This could also lead to a more humanistic and holistic approach to treating patients that encourages medical practitioners to rely on each other more openly, so that the patient feels as though they are being assisted by a team rather than by an individual.

The Future of Assisted Technologies

Bionics

Bionic prosthetics are an incredibly promising option in the not-too-distant future. One of the biggest complaints that came up across the studies, and that contributes directly to abandonment, is the issue of ease of use. Conventional prosthetics are heavy in weight. Bionics, on the other hand, represent a prosthesis that needs little, to no muscle power from the user, thanks to having their own power systems. A bionic that is electronically or mechanically powered offers critical support to the body. This flips the dynamics entirely. Instead of the user having to specialize their movements and support the prosthetic through rigorous training, a bionic prosthetic supports the user.

Unfortunately, bionics are currently too expensive and often require too much maintenance to be a preferable option in the present. This is, however, subject to change as technology gets more and more advanced. As with all technologies, bionics will likely undergo transformative changes as designers try to incorporate cost-friendly measures into their designs. It may not be long before their performance, cost, and maintenance become manageable, creating a future in which those with physical disabilities can choose functional replacements for a limb that function nearly as well as an actual organic limb.

Policy Changes

As referenced early on in the thesis, global legislature is starting to have a profound influence on how disability is dealt in society. The work of the United Nations, in particular, has had far-reaching consequences. The struggle now is in bringing the local level legal changes that would be necessary to make resources more accessible for those with disabilities.

One area in which this is profoundly important is, of course, in the continued improvement of the state funded ATDs. The state institutions are currently lagging behind the private institutions offering ATDs. India's mastery of modern technologies, particularly in its universities, continues to evolve with each passing day. With proper funding, it would most likely be possible to put together enough scientists and researchers to start manufacturing updated modern devices locally.

This would create new jobs for the manufacturers, lower the cost of importing/exporting parts, and improve ease of access for the end user. This will lead to a future in which prosthetics and other ATs produced in India can be on par with foreign competitors, allowing local governments to either make deals with or directly contract local designers to improve on the options currently available.

Education and the Engineering Institutes

In addition to providing more education on the factors that cause disabilities and the realities of disabilities, especially in rural areas, it will be important in coming years for places of higher education to contribute local studies into the needs of persons with disabilities in India, since so much of our data and technology still comes from overseas.

While there is nothing wrong with using international data as a baseline in growing industries, it is important to note that prosthetics are often designed with local needs in mind. Prosthetics that are designed for use in cooler urban climates are more prone to breaking down when exposed to warm rural settings and vice versa, not to mention the discomforts that can come from equipping a prosthetic not meant for one's own region. It would be better if engineering students from pioneering institutes like IITs, IIMs and from engineering colleges think about designing assistive technologies that suits the needs of local people.

Universal Design

As the principles of universal design catch on, society will naturally become more and more accessible to persons with disabilities. Universal design is an appealing concept for many developers, since making a product usable and comfortable for various end users leads to a direct increase in the reach of the product and thus its potential for revenue.

The struggle here is, of course, in the implementation. Some products (such as modular building structures) do require more creativity than others to incorporate universal design

principles, and thus often a larger budget, in order to make them useful to as many people as possible.

The upside is that a product made with universal design in mind only needs to be made once, then iterated on. Rather than design five different versions of the same product to accommodate slightly different needs, then conducting market research on how many of each of these designs to send out, universal design allows for a product to be made once and utilized across the entirety of the target audience. The budgetary constraints of manufacture can thus be counterbalanced by the improvements to models of maintenance and marketing. A product that is usable by everyone sells itself, as word of mouth gets around.

This also goes hand-in-hand with the humanitarian principles that are currently going strong internationally. Ever since the International Year of Disabled Persons (1981), awareness of disability and the problems faced by persons with disabilities have drastically improved. The general idea of utilizing persons with disabilities in the workforce and elsewhere, whenever possible, leads to a gradual improvement on the outcome as more and more CEOs and world leaders start to look toward these communities as untapped human resources who are not being allowed to utilize their full potential. Universal design will be one of the defining principles that allow cities and countries across the world to better utilize the people right there in their local area, who are ready to contribute given the means.

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Appendix A

INTERVIEW SCHEDULE FOR RESPONDENTS

1.BASIC INFORMATION:

A) Name

B) Age

C) Gender

D) Caste

E) Occupation

F) Type of disability

2 DETAILS OF FAMILY MEMBERS INCLUDING SIBLINGS:

SlNo.	Name	Relationship to the Child	Age	Occupation	Educational Qualification	Income

3 RESPONDENTS' PERCEPTION OF SELF(I&ME):

Autobiographical Narrative of the respondent

In the beginning respondents' will be asked to narrate the significant events of their lives in the form of a story. A respondent will be asked to describe using the third person, an autobiographical account of him/herself. The respondent for instance can be instructed as we are going to writeX's story. The beginning of the story can be specified as:

Anand was born on----------

When she was a baby----------

When she went to school----------

She was extremely sad when_----------

She got very angry on_____

She felt like shouting and crying when----------

She wanted to run away or do something himself/herself----------

Her parents were extremely happy when----------

When she grows up she wants to be----------

4) PHYSICAL APPEARANCE

I) What is that you like most about yourself as far as your appearance/looks are concerned.

II) Is there any occasion when some/any of your friends/family told you that you were looking good/nice? If yes, how did you feel then

III) what is that you dislike most as far as your appearance/ looks concerned? Why do you dislike it?

IV) Do Your friends /family pass any unkind remarks about your looks/

V) Does your siblings/Family members at any point of time commented or passed any unkind remarks about your looks.

VI) Have your parents at any point of time told you anything about your appearance? Then what was your reaction to it.

5) SOCIAL ACCEPTANCE (PEERS and FAMILY)

I) Do you like making friends? Why?

II). Do you like going to parties? why?

III) What kind of parties do you like to attend?

IV) With Whom do you feel comfortable while going to parties (like friend, Parents, grandparents, siblings)?

V) Has any friend/family members unkind to you on any such occasion?

VI) Have you noticed do your family members at times find it difficult taking you along?

6) RESPONDENTS AND THE FAMILY

I) Whom do you like the most in the family?

II) Why do you love him/her the most?

III) Do you share all your thoughts and secrets with him/her?

IV) Is it normal to discuss all your problems including your disability within the family?

V) Can you manage to do all your daily chores (e.g., going to the washrooms, getting ready, go to school, etc) on your own? Or does your mother, siblings or grandparents help you in doing these chores?

VI)What you and your family members do when all of you are together at home?

VII) Do you at any point of time stay alone in the house? In such situations how do you help yourself?

VIII) What does your family plan for you as far as marriage is concerned? Are you able to share all your feelings/ thoughts with your family members as far as plans for marriage is concerned?

IX) Does anyone in your family encourage in your studies?

X) What do your parents aspire for you? Do you think that your parents will be happy if you lead an independent life.

7) GOALS AND ASPIRATIONS

I) Do you want to study further and how much do you want to study?

II) Have you made any plans of your future marriage?

III) What do you want to become in life?

IV) What are your goals and aspirations with regard to

a) Your Studies b) Your Profession c) Your family d) The Society and e) The Disabled people.

INTERVIEW SCHEDULE FOR OTHERS (Parents and Para – Medical Staff)

1) What do you mean by disability?
2) According to your opinion who can identify disability of a child first?
3) What do you think that you need to do to overcome disability?
4) Do you think that government intervention is required in addressing disabled people?
5) What steps will you take to sensitise on the issue of disability?
6) Do you think that medical interventions/corrections can normalise the concept of disability?
7) Do you think that technological advancements can neutralise the concept of disability?
8) Do you think that present technology in India can accommodate the needs of persons with disabilities.

9) Don’t you think that societal corrections are also equally responsible to overcome disability?

Appendix B

GLOSSARY

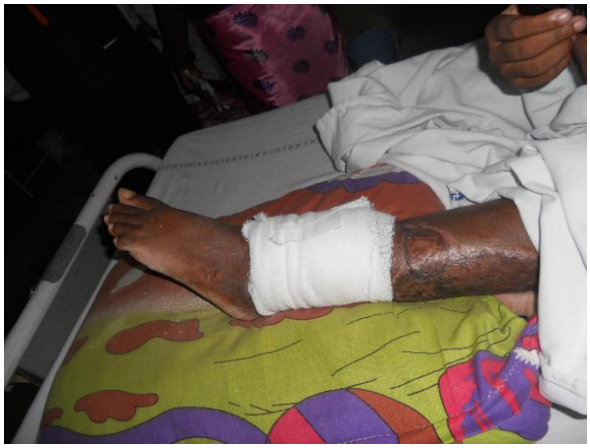
Aapaina:	On top of it
Abhisekham:	A Ritual to god (Bathing God with fruit juices)
Adharam:	Dependent
Adda pilla:	Girl Child
Amavasya:	No moon Day
Asthulu:	Properties
Badyita:	Responsibility
Bava:	Father’s Sister’s son/ Mother’s Brother’s son
Bhandena/ Bhandham:	Relationship
Bidda:	Son/Daughter
Brethktunam:	To live
Chaduvu:	To Learn/ Educate
Cheyalevu:	Can’t do anything
Choostamu:	Will see
Dabbulu:	Money
Evaru:	Who/Whom
Homamas:	Rituals in front of fire God
Ivi/ichi:	To give
Janma:	Birth
Kaalu:	Leg
Karchu:	To spend

Karma:	The sum of a person's actions in this and previous states of existence, viewed as deciding their fate in future existence
Karate:	A form of martial act
Kalyanam:	Marriage
Kalu leni Valu:	Absence of not having legs
Kastham:	Hard work
Katnam:	Dowry
Kula daivam:	Caste God
Kunti:	Limp
Kuntoda:	Crippled/ Derogatory way of Calling hey cripple
Na/Nadi:	Mine
Nadvalevu:	Unable to walk
Marwadi:	Money lender
Nuvvu:	You
Orey:	Derogatory way of calling before name instead of dear
Pampichali:	To send
Papam	Misdeeds
Pedda:	Big/Bigger
Pelli:	Marriage
Petali:	To Keep
Pilla:	Girl
Poorva Janma Papam:	Past Misdeeds
Pournima/Poornima:	Full Moon Day
Praptristratu:	To obtain
Puja:	Worshipping God
Putindi;	Was born
Runalu:	Past loans

Sariga:	Right way
Sheegramave:	Fast
Tanu:	S/he
Thala Ratha:	Written in Destiny
Tindi:	To eat
Udyogam:	Job
Vankara:	Twisted/Turned

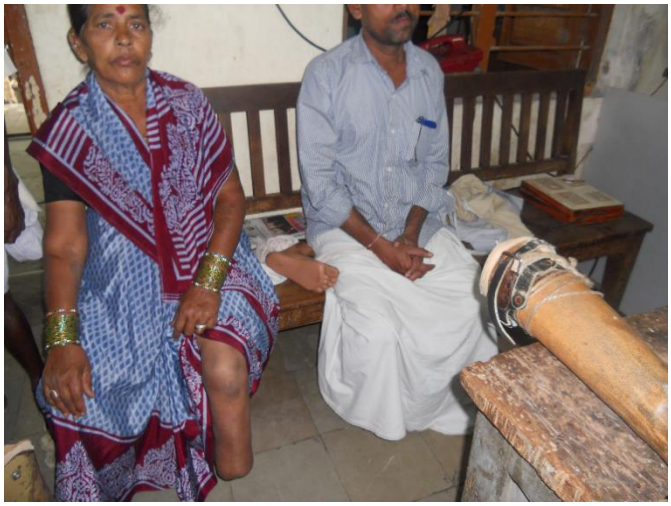
Appendix C

PICTURES FROM THE FIELD



Pic.1: Patient ready for amputation at IMS.

Pic 2: Light-weight material cut to the measurements of a limb. Ready for moulding.



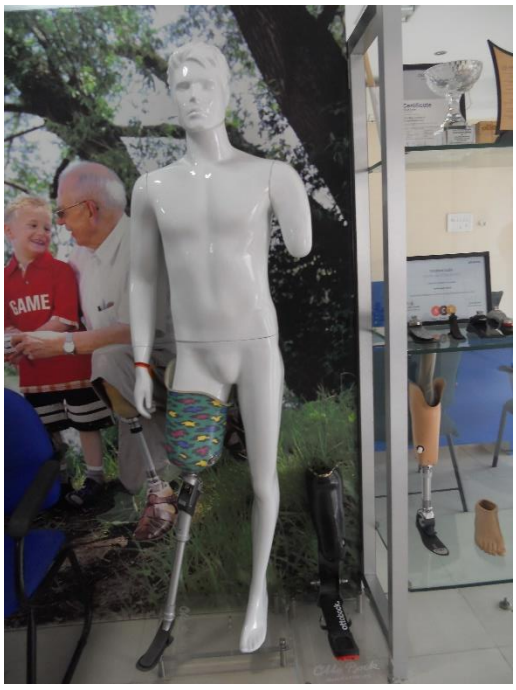
Pic 3: Two patients pictured with prosthetic limb in foreground.

Pic 4: Construction in progress.

Pic 5: Take special note of the uneven flooring at IMS – ALMU, a state-run organization.

Pic 6 : Orthofit is able to offer a wide selection of prosthetics.

Pic 7: Walking room at Orthofit; specially designed with developing a natural gait in mind.

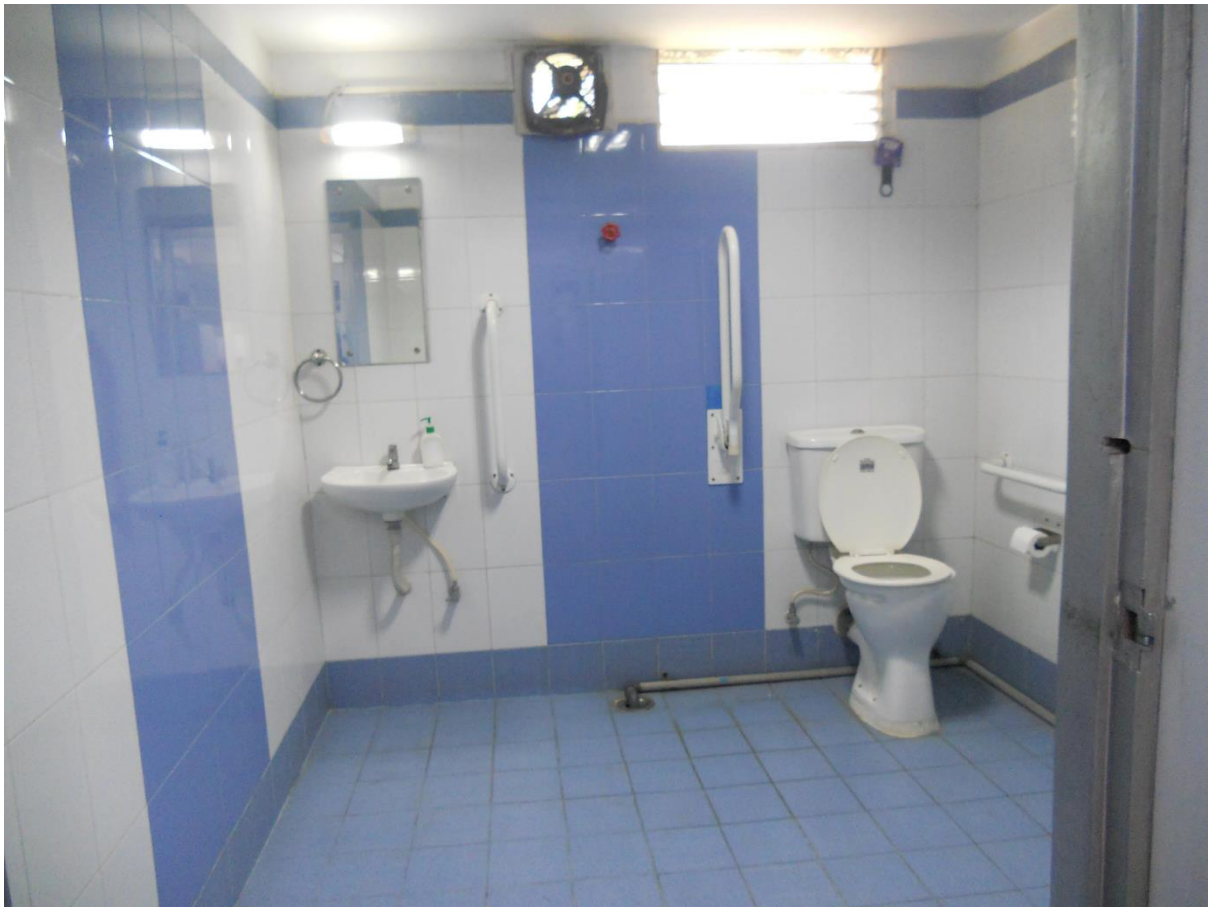


Pic 8: This device at Orthofit is called a C-Leg. It is a customizable leg modified with different materials for the user, and can be fitted with an electric motor chip.

Pic 9: Various material at Orthofit available for selection.

Pic 10: Construction and moulding can be done with advanced machinery, rather than by hand, as Orthofit demonstrates.

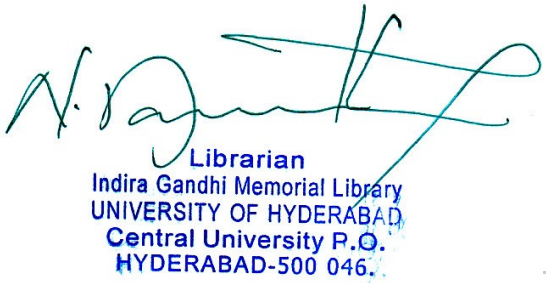
Pic 11: Orthotic brace pictured at Orthofit.



Pic 12: Accessible washrooms at Orthofit with wide open space for practical use with disabilities. Compare to uneven floors and cramped spaces at IMS - ALMU.

Disability, Identity and Assistive Technologies: A Sociological Study of Orthotics and Prosthetics for the Orthopedically Challenged

by K Pavani Sree



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Situating Census Data in Disability Discourse: An Analysis of Census 2011 and 2001

C. Raghava Reddy and K. Pavani Sree

Abstract

The present paper attempts to analyse the Census 2011 & 2001 data on People With Disability (PWDs) in terms of social indicators by situating it in the larger disability discourse. The paper also explores the significant trends by comparing 2011 data with 2001 data on PWDs. The paper observes that Census 2011 data report a considerable percentage of PWDs in the categories 'any other' and 'multiple disabilities'. Data on these two categories is incomprehensive to identify persons by the type of their disability. The paper argues that since disability is socially and culturally embedded, the Census enumeration of PWDs requires special attention and treatment for which the enumerators have to be trained appropriately.

Keywords: Disability, Census, Sex-Ratio, Aging, Social Categories

Introduction

Persons with Disabilities (referred as PWDs hereafter) constitute a significant part of the human society. Disability, although evolved through social interaction in the immediate (family) and wider (social) context, is a relative term in so far as different cultures define their norms of being and doing differently. 'Conceptions of disability are highly contextual and subjective' (Chand and Reddy 2012:31). However, disability as a universal phenomenon connotes disadvantage, incapability, deficiency, especially a physical or mental impairment, that restricts normal achievements. In other words, disability may be visible or hidden, may be permanent or temporary and may have minimal or substantial impact on a person's abilities.

It is no longer seen as the biological condition of an individual body, but it is perceived as a complex product of social, political, environmental and biological discourses. According to Mehrotra (2013:25) 'this categorization lies within the ambit of social, cultural, economic and historical matrices'. 'Persons with disabilities are the largest minority group in the world. It has been noted that there are more than 650 million people worldwide (two thirds of them live

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DCU | Ireland India Institute

Dublin 27 April 2018

Letter of attendance to the Second Postgraduate Conference on South Asia 26-27 April 2018

This letter confirms that K. Pawanii Shree has attended the Second Postgraduate Conference on South Asia, 26-27 April 2018 and presented a paper titled:

Social Security & the Disabled Women: A Sociological Understanding of Social Security Issues for Women with Locomotor Disabilities in India

The conference was organized by the Ireland India Institute of Dublin City University and held on Dublin City University All Hallows Campus.

Best wishes,

Ireland India Institute

27 APR 2018

Dublin City University

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Director, Ireland India Institute

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THE STATE, SOCIETY AND DISABILITY LAW IN INDIA: CHALLENGES FOR RIGHTS-BASED APPROACH

Organized by the Department of Sociology, University of Hyderabad

on 31-January & 1-February, 2018.

CERTIFICATE OF PARTICIPATION

This is to certify that K. Pavani Sree *has participated and presented a paper/ ~~chaired a session/Keynote Address~~ entitled* The Unheard Voices: A Sociological Understanding of Persons with Locomotor Disabilities in Accessing Assistive Technologies *in the UGC-SAP National Seminar on "STATE, SOCIETY AND DISABILITY LAW IN INDIA: Challenges for Rights-based Approach" organized by the Department of Sociology, University of Hyderabad on 31-January & 1-February, 2018.*

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